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A Conceptual Framework of the Experience  
of Future Disorientation in Adults Living  
With and Beyond Cancer

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PhD

2014

# A conceptual framework of the experience of future disorientation in adults living with and beyond cancer

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This thesis is submitted in partial fulfilment of the award of Doctor of Philosophy of the University of Northumbria at Newcastle

Research undertaken in the Faculty of Health and Life Sciences and in collaboration with Gateshead NHS Foundation Trust.

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## **Abstract**

**Background:** There has been little research into the area of future disorientation in adults living with and beyond a cancer diagnosis. Research conducted in this area tends to focus on women who have been treated for gynaecological cancer and to be cross-sectional. Therefore, little is known about the impact of future disorientation on other groups of people living with and beyond cancer, including men, and little is known about how the experience may change over time.

**Aims:** This thesis aims to develop a conceptual framework illustrating the experience of future disorientation. This was achieved by exploring what the consequence of future disorientation are, what factors cause participants to experience future disorientation and what factors prevent/reduce the impact of future disorientation.

**Methods:** This study utilised an interpretative phenomenological analysis approach (IPA) which informed all aspects of the data collection and analysis process. Eight patients attending follow up clinics in the North East of England were recruited and were interviewed on two occasions six months apart. The interviews were semi-structured and analysed using an IPA approach.

**Results:** The results of this study have shown that future disorientation can be experienced by men and women living with and beyond cancer, that it can persist over time, and have a number of consequences. A number of factors have been identified which may contribute to the experience of future disorientation such as cancer related fears, and anxiety. Furthermore a number of factors emerged which may protect patients from experiencing future disorientation, such as support networks and making lifestyle adjustments. This thesis constitutes an original contribution to knowledge as no work has previously sought to map out the conceptual framework of future disorientation or how it changes over time.

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## **Declaration**

I declare that the work contained in this thesis has not been submitted for any other award and that all of the work is my own. I also confirm that all opinions, ideas and contributions from the work of authors are fully acknowledged within this thesis.

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the School Ethics Committee and National Research Ethics Service (NRES) in May 2011 and October 2011, respectively.

Name: Grant James McGeechan

Signature:

Date: 26/06/2014

## **Chapter 1 – Introduction**

### **1.1 Personal Journey and Rationale for this thesis**

My interest in the area of cancer research began as I was approaching the end of my MSc in Health Psychology at the University of Stirling in 2009 and was contemplating continuing my studies to PhD level. Initially I was interested in research around the area of cancer screening and how to increase participation in cancer screening programmes. However, around this time my uncle was diagnosed with, and treated for cancer. With my uncle now living with and beyond cancer my focus shifted onto what it was like for a patient once they had finished their primary treatment for cancer.

Following this, I read an advert for a PhD being offered at Northumbria University which sought to look at the experiences of well-being amongst people living with and beyond cancer in the North East of England. I felt that this was a project which corresponded well with my own research interests. One of the novel areas which the project sought to explore that really caught my attention was around the area of future disorientation. Future disorientation focuses on the fact that people living with and beyond cancer are living with an uncertain future, and I was really interested in exploring what impact this had on their ability to look ahead and plan for their future.

Living with and beyond cancer is defined by the National Cancer Survivorship Initiative in the UK (Department of Health, 2010) as: “Anyone who has received a diagnosis of cancer including those who are still undergoing treatment, those who are in remission following treatment, those who have been cured, and those with advanced disease are deemed to be living with and beyond cancer.” All of the participants in this study would therefore be classed as living with and beyond cancer as they are in remission following treatment.



While I did not have any experience with this population, prior to applying for this PhD, I had considered applying to the Chief Scientists Office for funding around the area of increasing uptake of colorectal cancer screening. Therefore, I had already done a considerable amount of background reading around cancer in general. This reading alerted me to the fact that the number of people living with and beyond cancer was rising (Costanzo, Ryff, & and Singer, 2009). This also enlightened me to the fact that people who were living with and beyond cancer can face a number of adverse impacts of cancer, such as: depression anxiety, guilt, biographical disruption, and fear of recurrence (Black & White, 2005; Cayless, Forbart, Illingworth, Hubbard, & Kearney, 2010; Gao, Bennett, Stark, Murray, & Higginson, 2010; Glanz & Lerman, 1992; Handschel, Naujoks, Kubler, & Kruskemper, 2012; Herschbach, & Dinkel, 2014; Humphris et al., 2003; Klostevsky, Schimpff, & Senn, 1999; Montel, 2010;). Furthermore, I knew that experiences of these disorders were not stable constructs (Buddeberg et al., 1996; Ghazzali, Cadwallader, Humphris, Ozakinci, & Roger, 2012). This prior knowledge therefore, led me to believe that the ability of a patient to look ahead and plan for the future may also be temporal in nature.

Research has previously sought to explore how living with and beyond cancer can impact on how patients view and plan for their future. This research into future disorientation however, has focussed only on women treated for gynaecological cancer (Maughan & Clarke, C. L., 2001; Roberts & Clarke, C. L., 2009) and survivors of breast cancer (Breaden, 1997). No studies have been uncovered thus far looking at this phenomenon in men living with and beyond cancer. It should be noted however, that with only a handful of studies in this area, research into future disorientation in this population is still at the early stages. Therefore, a conceptual framework of what contributes to future disorientation, what may help prevent it, and what the consequences of future

disorientation are, is needed in order to fully understand its impact. As will become apparent in the literature review, patients' experiences of the various impacts of cancer, and its treatment, do not appear to be stable over time, therefore it is important to study future disorientation at more than one time point.

After deciding where my research would lie in this area, I had to ascertain the best method to investigate the topic. As this was an exploratory study aiming to develop a conceptual framework, I felt that the best way to explore the experience of future disorientation in this population was to use a qualitative approach. This will be discussed in more detail in Chapter 3. Furthermore, a qualitative approach fits in with my epistemological standpoint, where I believe that the experience of each individual is unique in relation to the phenomenon being studied. Once I had decided that the research was best undertaken using a qualitative approach, I then had to select an appropriate qualitative methodology. My background in research before undertaking this PhD was focussed entirely on quantitative methods. Therefore, I had to conduct a substantial amount of reading around qualitative methods, and research paradigms in order to establish my philosophical position. Following this background reading, I felt I could then go on to select an appropriate methodology for my research. After consideration of my ontological and epistemological positions, which will be discussed in more detail in Chapter 3, and consideration of other methodologies, Interpretative Phenomenological Analysis (IPA) was chosen as the most appropriate method of analysis to utilise in this research. IPA not only reflects my philosophical stance, but also focuses heavily on participants lived experience. I feel that IPA places emphasis on experience at the individual level initially, before trying to make sense of experience for a group, where as other qualitative methodologies tend to focus on the experience of the group in the first instance, using individual accounts to support their arguments.

As this area is under-researched I decided that the study should be left open to as wide a population of patients as possible. Therefore, I did not set out to recruit patients with any particular tumour type. However, given that I wanted to look at the experience of males and females living with and beyond cancer I wanted some of the recruited participants to have undergone treatment for the same cancer to make comparison of similar treatments possible. Therefore, it was expected that a number of male and female patients would be drawn from cancers that affect both genders such as colorectal cancer, lung cancer or malignant melanoma (Cancer Research UK, 2013b). Furthermore, given that future disorientation has already been documented in patients with gynaecological and breast cancer, it was expected that some of the female participants would be drawn from these populations.

The method of data collection, like the method of data analysis, was influenced heavily by the research paradigm, constructivism. I wanted the data to be patient-centred and to explore the concept of what living with and beyond cancer means to them, as individuals, in relation to their future. As is recommended for an IPA study, I used semi-structured interviews as my method of data collection (Smith, J. A., Flowers, and Larkin, 2009). This would allow the patients to talk about what issues were important to them in their post-treatment lives. It was hoped that the patients would naturally talk about how they felt about their future, and if not, then the focus of the interview could be shifted in that direction. The use of semi-structured interviews allowed me to gain in depth-knowledge of the experience of a patient once they had finished treatment and to understand what factors were important to them. This could then align with their views of the future to see which factors in their lives could be associated with their ability to make plans for their future.

The chapters that follow will demonstrate that the approach used in this project has allowed me to develop a detailed understanding of the experience of future disorientation for my

research participants. Having outlined the reasoning why I have undertaken a PhD in this area, a brief summary of the outline of my thesis is provided below.

## **1.2 Structure of the thesis**

The next chapter (Chapter 2) provides an overview of the literature. The literature in this chapter was identified primarily from searches of scientific databases, and from searching the reference sections of identified papers, to find additional key papers. The evidence identified in the literature was used in conjunction with the results which emerged from the interviews in the development of the conceptual framework which is outlined in Chapter 8.3.

The third chapter of this thesis outlines the world view of the researcher and the arguments in support of a qualitative methodology, with particular reference to the ontology and epistemology. This chapter also provides a critical analysis of other qualitative methodologies that are compatible with my ontological and epistemological position and outlines arguments as to why IPA is the best method to answer my research questions. Chapter four summarises the development of the project and moves onto outline the details of the recruited sample, the creation of a semi-structured interview schedule, and the steps taken for data collection and analysis. A discussion around of issues surrounding the validity of qualitative research in general, and of IPA in particular, is also provided here.

Chapters five, six and seven outline the results of the final analysis conducted from the interviews at both time points, presented on a theme by theme basis. Four super-ordinate themes emerged from the interviews, with each super-ordinate theme containing a number of sub-themes. These will be discussed in turn relating to each participant. The results outlined in Chapters five, six and seven will be summarised in Chapter eight with reference to the literature and research aims and objectives set out in this chapter. A conceptual

framework is then proposed outlining potential causes of future disorientation, factors which may reduce its impact, and the negative outcomes of future disorientation. The discussion in Chapter eight then moves on to exploring the strengths and limitations of this particular research study before future areas of research are outlined.

### **1.3 Research Aims and objectives**

The principle aim of this thesis was to provide a conceptual framework of future disorientation as experienced by men and women living with and beyond cancer. In order to achieve this, a number of objectives were set out. In order to understand what causes future disorientation, what impact it has on patients' lives, and what may prevent patients from experiencing future disorientation, a number of qualitative interviews were conducted. These interviews were conducted using an IPA approach, which fits in with the researcher's philosophical standpoint of social constructivism. The researcher feels that that human experience is neither observable nor categorical, rather he assumes the position of Carr and Kemmis (1986) that the experience of an individual is unique and only exists in the context of their experience of it. Therefore a methodology had to be chosen which reflected this position and emphasised the uniqueness of the individual. The process behind selecting an appropriate methodology is discussed in more detail in Chapter 3.3.

The interviews were guided by the findings from the literature review and focussed on a number of consequences of a cancer diagnosis which may lead to future disorientation. In order to understand the long term impact of future disorientation it was decided to follow patients up for a second interview, six months after the first to see if their experience of future disorientation had changed. The research aims are presented in more detail at the end of the literature review chapter (2).

## **Chapter 2 – A literature review exploring the long term consequences of cancer treatment.**

An overview of the literature regarding the experience of future disorientation in adults living with and beyond cancer is presented in this chapter.

The purpose of the literature review was to identify papers which had looked at future disorientation in people living with and beyond cancer, however given that research in this area is relatively new, similar papers were sought for other chronic conditions to give an overview of the phenomenon. Keywords for the literature search were agreed upon in collaboration with the information scientist based within my faculty of Northumbria University. These are outlined in table 2.1 below, along with details of the databases that were searched. Few IPA studies have been conducted longitudinally, therefore the review includes other studies in the area of cancer which have utilised a longitudinal approach. Finally, in order to fully understand future disorientation in a cancer population, literature on the impact of cancer as a long term condition was identified in order to assess which factors may contribute to a patient's experience of future disorientation. Once papers had been identified which were relevant to this literature review, their reference lists were searched to identify any additional relevant papers.

**Table 2.1 – Databases and keywords used for literature search**

Database	Keywords – <i>all databases searched with the following terms</i>
PsychArticles	Future Disorientation
CINAHL	Biographical Disruption AND cancer surviv*

**Table 2.1 Continued**

Medline	Uncertainty AND cancer surviv*
ProQuest Nursing and Allied Health Source	Fear AND cancer surviv*
Applied Social Sciences Index and Abstracts (ASSIA)	Recurrence AND cancer surviv*
Web of Science	Longitudinal AND Interpretative Phenomenological Analysis
	Psychological wellbeing AND cancer surviv*

## **2.1 Introduction**

Due to advances in treatment and detection, approximately two in three adults diagnosed with cancer can expect to survive more than five years (Costanzo, Ryff & Singer, 2009). The World Health Organisation (WHO) now consider cancer to have a chronic, rather than a terminal, disease trajectory (Jiwa et al., 2008). There are currently over 1.8 million people in the UK living with and beyond cancer and, with advances in medical care and a growing elderly population, this number is set to rise even farther (Appleton, L. Goodlad, Irvine, Poole, & Wall, 2013).

Colorectal cancer is the third most common form of cancer in the United Kingdom for males, and the second most common cancer for females. Thirteen per cent of all new cancer diagnoses in the UK are colorectal cancer, with about 41,000 new cases, and 16,000 deaths reported in 2010 (Cancer Research UK, 2013a). With 53% of males and 54% of females expected to survive for five or more years after diagnosis this means that there are

around 143,000 people in the UK living with and beyond colorectal cancer at any one time. Furthermore, with the number of new cases of colorectal cancer expected to rise to around 58,000 per year by 2030 (Mistry, Parkin, Ahmad & Sasieni, 2011) this represents a potentially large group of patients who may be susceptible to future disorientation.

Cervical cancer affects around 3,000 women a year in the United Kingdom. The introduction of the Papanicolaou (Pap) test has resulted in earlier detection of cervical cancer, which has seen survival rates increase dramatically in the last 40 years (King, Kasper, Daggy, & Edmonds, 2014). Around 83.6% of women diagnosed with cervical cancer will survive for at least one year, with 67% surviving for at least five years (Cancer Research UK, 2013d). Ovarian cancer, on the other hand, is the fifth most common cancer affecting women in the UK, with 6,500 new cases diagnosed each year. One year survival rates for ovarian cancer is around 70%, which drops to around 40% at the five year mark. In 2010, over 25,000 women in the UK were living with and beyond these gynaecological cancers representing another large group of patients who may be experiencing adverse consequences of cancer and cancer treatment (Cancer Research UK, 2013c).

## **2.2 Consequences of a cancer diagnosis and treatment**

As numbers of cancer survivors increase, a growing number of people are living with and beyond initial cancer treatment and, as a consequence, more people are likely to experience adverse symptoms of cancer treatment. Studies have shown that people who have finished treatment can suffer from physical, and psychological symptoms. For example it has been reported that approximately 8-25% of newly diagnosed cancer patients experience depression or anxiety (Irwin, Olmstead, Ganz, & Haque, 2012; Jansen, Koch, Brenner, & Arndt, 2010; Krebber, Buffart, Kleign, Riepma, de Bree et al, 2014; Osborn, Demoncada & Feuerstein, 2006; Watson, Homewood, Haviland, & Bliss, 2005) compared to 0.5-9.8% of



the general population (Cerimele, Chwastiak, Dodson, & Katon, 2014; Ohayon & Schatzberg, 2002). Patients may also exhibit feelings of guilt, fear, anger, and emotional distress, and biographical disruption (Bury, 1982; Gao, Bennett, Stark, Murray, & Higginson, 2010; Giese-Davis, Conrad, Nouriani, & Spiegel, 2008; Glanz & Lerman, 1992; Klostevsky, Schimpff, & Senn, 1999; Hubbard, Kidd and Kearney, 2010; Love, Thompson, & Knapp, 2014; Navon & Morag, 2004), although the degree to which these outcomes are experienced may fluctuate over time (Buddeberg et al., 1996; Ghazzali et al, 2012; Hart, Latini, Cowan, & Carroll, 2008; Lowe & Molassiotis, 2011; Molassiotis, Lowe, Blackhall, & Lorrigan, 2011; Savard, & Ivers, 2013). Furthermore, these conditions can all affect health-related quality of life (HRQOL) (Ashing-Giwa et al., 2009; Nordin, Berglund, Glimelius, & Sjöden, 2001). Future disorientation may also be a consequence of a cancer diagnosis, and factors which may contribute to a patient's experience of this, along with factors which may help prevent it, are discussed in more detail later in this chapter. As future disorientation has not received much attention in the literature, it is important to first look at consequences of living with and beyond cancer as this may give an idea as to how future disorientation may progress over time, what may cause the experience and what may prevent a someone from experiencing future disorientation.

A study by Gao et al (2010) assessed how distress experienced by patients changed over time, by measuring patients at three different stages in their cancer journey. Three groups of participants were recruited for this study, patients from a cancer outpatient group, palliative care patients, and people from the general population of cancer patients who had completed the Health Survey for England. This study demonstrated that average psychological distress scores were highest for palliative care patients, with those who had finished treatment having the next highest scores, and cancer outpatients scoring the lowest. This highlights that psychological distress continues throughout the cancer

trajectory and worsens towards end of life care. However, there is a significant limitation with this study relating to the recruited population. While this study purports to be a comparison of distress over time, the participants for each time point were recruited from different populations so that patients in the palliative group were not the same patients who had been recruited for the cancer outpatient group. In order to truly assess the changing nature of distress amongst patients with cancer it would be appropriate to follow the same cohort of patients over time rather than recruiting different cohorts for various stages of the cancer journey as it is possible that the group of patients who formed the palliative cohort may have been particularly distressed throughout their cancer journey, and we therefore cannot attribute their distress to their stage of illness.

People living with and beyond cancer may also develop feelings of guilt. For example, in cases where patients are, or have previously been smokers, guilt may be associated with feeling that they are responsible for their cancer (LoConte, Else-Quest, Eickhoff, Hyde, & Schiller, 2008). LoConte et al (2008) found that smoking status was a significant factor in developing feelings of guilt, and shame, in relation to a lung cancer diagnosis. There was a small reduction in feelings of guilt and shame over time, however the differences were not significant. Participants who were current, or previous smokers, expressed greater feelings of guilt and shame than those who had not been smokers. Additionally, those with lung cancer were more likely to feel that their behaviours had contributed to their cancer developing than smokers/previous smokers in a comparison group of breast and prostate cancer. However, while this study is longitudinal in nature assessing the same cohorts of patients over time, the results may have been more valid had the author reported the length of time since patients were diagnosed. There appears to be a reduction in feelings of guilt and shame over time, and therefore one would expect that patients would score higher on these factors in the earlier stages of their cancer journey. Furthermore, while this paper

reports patients suffering from multiple symptoms of cancer, there is no discussion of the relationship between the symptoms. For example it would be interesting to know if patients who reported depression were more or less likely to also express feelings of guilt. Feelings of guilt have also been observed in patients diagnosed with colorectal (Sjovall, Gunnars, Olsson & Thomé, 2011) and gynaecological (Sacerdoti, Lagana & Koopman, 2010) cancers, related to a lack of intimacy and sexual contact with their partners.

As discussed previously, depression is one of the most commonly reported outcomes for people living with and beyond cancer. Kim et al (2008) found that, alongside fatigue, depression was the most common symptom experienced by women who were approximately 4 years post treatment for breast cancer. They highlighted that 43.2% of patients reported being fatigued, 3% reported being depressed and 21.9% reported feeling both fatigued and depressed. Ramsey, Berry, Moinpour, Giedzinska and Andersen (2002) also found that adults living with and beyond colorectal cancer had higher rates of depression than the general population.

The above studies highlight that there are numerous adverse impacts of a cancer diagnosis and subsequent treatment such as, distress, depression, and feelings of guilt. Furthermore these consequences can persist for years after treatment, and can affect patients regardless of cancer type. Therefore, it is possible that the experience of future disorientation as a result of cancer may also long term, and there is a need for research looking at its long term impact. Dodd and colleagues have suggested that research should focus on 'symptom clusters' and how the management of multiple symptoms can impact on patient's lives following treatment for cancer (Dodd et al, 2001a; Dodd, Miaskowski, & Paul, 2001b). While the above studies have discussed multiple consequences of cancer treatment, they still discuss these symptoms in isolation from each other and very little attention has been paid to the interaction of symptoms. The lived experience of multiple symptoms of cancer

can have a negative impact on the lives of those living with and beyond cancer (Henoch & Lövgren, 2014; Maguire, R. Stoddart, Flowers, McPhelm, & Kearney, 2014; Wang, Tsai, Chen, Lin, & Lin, 2008) and therefore research should focus on how symptom clusters can affect adjustment to cancer, as rarely do these symptoms occur in isolation. The notion of symptom clusters is important in the context of this present thesis as we are trying to uncover what factors may lead to the experience of future disorientation, and it may be that multiple consequences of cancer may be lead to, or worsen the impact of future disorientation. With this in mind, it will be important when forming the conceptual framework to look at the interaction of various symptoms of cancer, and how these might impact on the experience of future disorientation.

### **2.3 Future Disorientation**

The principle aim of this thesis is to explore the impact of future disorientation in people living with and beyond cancer, to determine what may cause future disorientation, and what factors may help prevent it. Prior to looking at the literature on future disorientation it is important to first define what is meant by the term. Future disorientation in relation to cancer is defined by Maughan and Clarke, C. L., (2001) as a response to the chaos that emerges out of a cancer diagnosis and a realisation that people who have had a cancer diagnosis are living with an uncertain future. Patients can be left with a feeling that their lives have been disrupted due to illness, and future disorientation may occur when patients fail to adapt to the subsequent changes to their lives caused by their illness (Roberts & Clarke, C.L., 2009). However, not all patients will suffer from future disorientation. If patients learn to adapt to their new future, they can be left feeling like a stronger person because of their experience (Appleton, L., et al, 2013).

There is a paucity of research exploring future disorientation and its consequences. To date only two papers were identified which explicitly explore the impact of future disorientation in cancer, both of which were conducted with females living with and beyond gynaecological cancer (Maughan & Clarke, C. L., 2001; Roberts & Clarke, C. L., 2009). Maughan and Clarke, C. L., (2001) looked at psychological, social, and sexual adaption in women following major pelvic surgery as a result of gynaecological cancer and found that future disorientation was an evolving theme. Most of the women interviewed expressed future disorientation, and it manifested itself in a number of ways. Participants reported feelings of distress related to infertility due to treatment, the effect of illness on family life, and trying to reconstruct their future. Women were especially susceptible to future disorientation if they were childless or had planned on having more children at the time of their surgery. While this study introduces the idea that infertility issues can lead to feelings of future disorientation in women living with and beyond cancer there are a few limitations with this study. As this was a cross-sectional study then there is no way of knowing what the long term impact of infertility is in relation to future disorientation. Furthermore, no information is given relating to what stage of the cancer journey patients are on, as it may be that distress is highest just after surgery and women who have recently been treated may benefit more from interventions by the clinical nurse specialist than those further along their cancer journey.

Roberts and Clarke, C. L., (2009) also found feelings of future disorientation emerging in women who were living with and beyond gynaecological cancer. While the above study found that future disorientation could manifest itself in concerns about infertility and not being able to have children, this study focussed on how women reconstruct their future after surgery and their conceptualisation of risk. Fear of cancer recurrence was a common theme amongst the participants and appears to be associated with future disorientation.

The experience of fear of cancer recurrence is discussed in more detail later in this chapter (2.4). Even when there is no evidence of cancer returning, patients described feeling ‘a cloud’ coming over them and a fear that they may still die from cancer. This may, inevitably, influence how they reconstruct and plan for their future. Like the study by Maughan and Clarke, C. L., (2001) these results suggest that women may be left feeling that they have put the future life they had envisioned on hold. In order to regain orientation they must recognise their new lives and adapt to changes following cancer treatment. While not using the term future disorientation, Breaden (1997) found similar themes emerging in a study with women treated for breast cancer; issues around the future arose in a number of the participants. Many of the participants in this study reported feeling that they were unable to plan for their long term future, something which non-cancer patients may take for granted. Ruth and Modi (2003) similarly found that older cancer patients were particularly concerned about their future life expectancy. While the above studies have introduced the idea that future disorientation can be caused by infertility issues they have only focussed on women living with and beyond cancer. Many cancers can lead to infertility issues in men and therefore future studies should aim to investigate whether or not men are susceptible to feelings of future disorientation. Furthermore, all of the above studies are cross-sectional, many of the symptoms of cancer discussed in Chapter 2.2 have been long term outcomes, therefore future disorientation should be studied longitudinally in order to fully understand the experience.

Similar results have also been found in patients who have suffered a stroke. Like patients diagnosed with cancer, they are psychologically unprepared for their illness (Burton, 2000), are living with an uncertain future (Lawrence & Christie, 1979; Reynolds, 2012), and have been found to suffer from fears of having another stroke (Townend, Tinson, Kwan, Sharpe, 2006). Research has been conducted which looks at the inability of stroke

patients to make future plans following illness. For example, a study by Green and King (2009) found that men who had suffered a stroke, and their wives, felt that the future which they had envisioned, both in the short- and long-term, had changed. This resulted in a feeling, for some, that their future was in jeopardy. However, like patients with cancer, not all stroke patients will have issues around planning for the future and for some couples this was actually a positive experience as it led to them being more open and honest as a couple and led to more family activities.

While these studies are interesting in that they introduce the idea of future disorientation in cancer, they only focus on women who have been treated for cancer. However, sexual dysfunction may also be a consequence of treatment for men who have been diagnosed with colorectal cancer and concerns about infertility after surgery may also be an issue in this population (Den Ouden et al, 2012). As noted in the studies above by Maughan and Clarke, C. L., (2001) and Roberts and Clarke, C. L., (2009), sexual dysfunction may be a potential cause of future disorientation. Therefore, male patients living with and beyond cancer may also be at risk of future disorientation. Fear of cancer recurrence is also a common experience for men and women living with and beyond cancer, regardless of tumour location (Handscheil, et al, 2012; Herschbach, & Dinkel, 2014; Pedersen, Rossen, Olesen, von der Maase, & Vedsted, 2012). Roberts and Clarke, C. L., (2009) linked fear of recurrence to a patient being unable to adapt and reconstruct a future life. Therefore it is possible that future disorientation is something which affects other groups of cancer patients; as will be discussed later in this chapter (2.4), fear of recurrence is a common concern reported by patients regardless of tumour location.

However, it must be stated that future disorientation may not be experienced by all cancer survivors and many can be left feeling optimistic about their future (Towsley, Beck, & Watkins, 2007). As patients move into survivorship they begin to think of time in cycles

with the date of cancer diagnosis or treatment being etched in their minds, each year then becomes a new beginning and the reclaiming of their future (Breaden, 1997). Furthermore, those patients who accept the changes to their lives which come with a cancer diagnosis are able to adapt to a new future and may not experience future disorientation (Maughan & Clarke, C. L., 2001; Roberts & Clarke, C. L., 2009). Of those studies which have explored future disorientation, none have focussed on why some patients do not experience future disorientation. Therefore, this chapter also explores what factors help prevent other consequences of a cancer diagnosis which was used to inform the conceptual framework around factors which may help a patient adjust to a disrupted view of their future.

There is no validated measure of future disorientation, although there is a future orientation scale (Saigh, 1995). This scale was designed for children and assesses future thinking on employment, family life, social relationships, and general expectations of the future. It has been used extensively in the study of post-traumatic stress disorder (PTSD) in war zones to compare the future attitudes of children living in those conditions with a general population (Solomon, & Lavi, 2005; Schwarzwald, Weisenberg, Solomon, & Waysman, 1997). This measure would not be appropriate for the study of future disorientation in adults living with and beyond cancer, primarily because over 60% of cancer diagnoses are in people over 60 years old (Goldzweig et al, 2009). Also, because it has been developed for children, it does not include a component on infertility or sexual dysfunction and lacks questions on fear of recurrence which the studies above have demonstrated could be associated with the experience of future disorientation (Roberts & Clarke, C. L., 2009). Furthermore the unvalidated cancer rehabilitation questionnaire (Nicholas, et al, 2006) has a section on future orientation, including the ability to make future plans, however like the future orientation scale, it does not cover infertility, sexual dysfunction, or fear of recurrence. Therefore, there is a clear need for a reliable measure of future disorientation for use both clinically



and for research. However, before this can be developed, it is essential that a fuller understanding of the nature and experience of future disorientation is acquired. The present study seeks to address this important gap by developing a conceptual framework that outlines the antecedents of consequences of future disorientation in the context of cancer survivorship.

In summary the above studies have introduced the concept of future disorientation as a consequence of suffering a life threatening illness; however, there are a number of limitations of the research into this concept. Firstly, future disorientation has only been explicitly explored amongst women living with and beyond cancer in relation an inability to adapt to a new life without the prospect of having children. However, infertility is a realistic consequence for men who have been treated for cancer: such as colorectal cancer. Furthermore, the above studies are all cross-sectional and therefore do not provide any indication as to how future disorientation develops over time. Other studies, while not explicitly investigating future disorientation, have found that patients with breast cancer, or those who have suffered a stroke can have concerns about making future plans. The current research will aim to fill the gaps in knowledge identified in the studies discussed above in order to develop the conceptual framework of the experience of future disorientation. The first two sections of this chapter have identified that future disorientation is a potential consequence of cancer for both men and women. Furthermore, the various impacts of cancer and its treatment described in Section 2.2 have highlighted that the experience of future disorientation may be long term. The following sections of the literature review will seek to identify other possible causes of future disorientation before moving on to factors which may prevent people from experiencing future disorientation.

## **2.4 Fear of Cancer Recurrence**

Fear of cancer recurrence (FoR) can be defined as a feeling of concern that cancer will return at an undetermined point in the future after treatment has finished. This is a common concern amongst those treated for cancer (Handsichel, et al, 2012; Herschbach, & Dinkel, 2014; Pedersen, et al, 2012) and is experienced by both men and women (Humphris et al, 2003; Im et al, 2008; Llewellyn, Weinman, McGurk and Humphris 2008; Northouse, Schafer, Tipton, & Metivier, 1999; Savard & Ivers, 2013). Research has linked the experience of FoR with a reduction in quality of life (Campbell, B., Marbella & Layde, 2000), and increased psychological morbidity (Hodges & Humphris, 2009; Hong, Hu, Paciorek, Knight, & Carroll, 2010). Estimates of the prevalence of FoR vary largely between cancer groups, and even studies looking at the same cancer type have reported vastly different rates of FoR. For example, Llewellyn, Weinman, McGurk and Humphris (2008) reported that FoR amongst head and neck cancer patients can vary from between 50% and 83%. FoR has also been observed in patients with colorectal cancer (Taylor, Richardson and Cowley 2010; Taylor, Richardson and Cowley 2011) and those with gynaecological cancer (Myers et al, 2013).

Estimates of actual recurrence of colorectal cancer range from 5-69% (Frykholm, Pahlman, & Gilmelius, 1995) within two years of surgery, therefore, it is reasonable to assume that fear of cancer recurrence amongst patients living with and beyond colorectal cancer may also be high. Indeed, Taylor, et al (2011) conducted semi-structured interviews with sixteen patients who had finished treatment for colorectal cancer and found that fear of recurrence was a common theme. Participants described feeling that cancer can come back at any time, or describing a huge fear element hanging over them all the time. However, while describing that fear of cancer returning was a common concern amongst participants,

the author provide only one quote relating to FoR, therefore it is unclear how many participants in this study actually reported concerns about recurrent cancer.

FoR has also been observed in women treated for gynaecological cancer. Myers et al, (2013) investigated FoR in women who had been diagnosed with gynaecological cancer and found that it was commonly reported by participants in their study. Of the 150 women who took part in this research, 47% reported moderate to high levels of FoR. In particular they found a relationship between age and FoR, with younger women reporting higher levels. Furthermore, functional impairment also appeared to be associated with FOR, with higher levels of functional impairment being related to greater reports of FoR. However, a limitation of this study was that it was cross-sectional in nature. The authors assert that fear of recurrence is greater the closer a patient is to diagnosis, therefore this study could have been strengthened by re-administering the concerns about recurrence scale at another time point. Furthermore, while the main focus of this study was to assess prevalence of recurrence fears amongst women with gynaecological cancer, patients were also measured on the Beck Depression Inventory; however there is no mention of a relationship between depression and fear of recurrence. This relates back to what was discussed in the previous section that while much research acknowledges the presence of multiple symptoms after a diagnosis of cancer, few investigate the relationship between symptoms and how this affects patient outcomes.

There is some debate in the literature relating to the long-term experience of future disorientation. Some studies have reported that the experience of fear of recurrence reduces over time (Ghazzali et al, 2012), whilst others have reported that the experience is intermittent and fluctuates over time (Hart et al, 2008; Savard & Ivers, 2013). However, the results of a recent systematic review would support the findings of Ghazzali and colleagues (2012) and suggests that fear of cancer recurrence is something which persists

for years after initial diagnosis, but being most severe close to diagnosis (Koch, Jansen, Brenner & Arndt, 2013). The issue around the stability of FoR is important in the context of this thesis as if FoR is linked to future disorientation, something which is explored as one of the aims of this thesis, then it is possible that the experience of future disorientation may also be intermittent. This therefore suggests that in order to fully understand the experience of future disorientation and its association with fear of recurrence then it is important to speak to patients at more than one time point. This will not only aid in the conceptual framework of future disorientation in determining if it is something which is a long term consequence of cancer, but looking at participants' FoR will allow for a deeper understanding of their relationship over time to develop. The findings by Taylor, Richardson and Cowley (2010; 2011) reported above suggest that fear of recurrence may be associated with future disorientation amongst patients who have been treated for colorectal cancer. Furthermore, the work of Roberts and Clarke, C. L., (2009) also identified a link between fear of recurrence and future disorientation in patients who have been treated for gynaecological cancer as discussed in Chapter 2.3.

Fear that cancer may come back can lead to future uncertainty and an inability to move on, which may result in not being able to plan for the future. This is important in the context of the current research as it informed the conceptual framework in terms of which factors may lead to the experience of future disorientation and led to the research aim of exploring the relationship between FoR and future disorientation. A limitation of the above studies relating to fear of recurrence is that no focus is paid to what may cause fear of recurrence, or what factors may help to reduce its impact. If we know that fear of recurrence is a common concern amongst patients diagnosed with cancer then research should focus on potential causes of fear of recurrence. Furthermore, as highlighted by Koch and colleagues (2013), the experience of fear of recurrence is highly intermittent and can be related to a

number of factors, a limitation of the above studies is that for the most part they are cross sectional in nature and do not take account of the fluctuating nature of fear of recurrence. This highlights the need for longitudinal research when investigating the consequences of cancer treatment.

## **2.5 Occupational Impact**

The ability to return to work following a cancer diagnosis is something which can have both financial and psychological implications for patients (Kennedy, Haslam, Munir & Pryce, 2007; MacMillan Cancer Care, 2013). Concerns over future careers can be a major issue with cancer survivors, who face an increased risk of unemployment, early retirement and are less likely to be re-employed (Kiserud, Dahl, Loge, & Frossa, 2014; Tritter & Calnan, 2002). Amir, H., Gatab, & Shayan (2011) observed that people treated for cancer had a strong desire to return to work, with the primary reasons why people want to get back to work being a desire for normality, and financial pressures. However, there is a chance that even if they want to return to work, cancer patients may face a number of barriers which prevent them from doing so, such as age at time of diagnosis (Carr & Kemmis, 1986), lower levels of education (Pélissier, Fontana, & Chauvin, 2014; Ussher, Kirsten, Butow, & Sandoval, 2006), tumours being at an advanced stage at the time of diagnosis (Bottorff et al., 2008), and cognitive problems resulting in reduced productivity (Kiserud et al., 2014).

Functional impairment related to tumour location can also act as a barrier to employment following treatment for cancer. Charmaz (1994) reported that 71% of head and neck cancer patients in their study returned to work after 6 months, and that many participants suffered anxiety about returning to work in relation to oral dysfunction and social eating. Those patients that had not returned to work identified oral dysfunction, loss of appetite, deteriorated social functioning, and high levels of dysfunction as barriers to employment.

In women with breast cancer, long term absence from work is quite common (Mehnert, 2011), with stage of disease at diagnosis (Bradley, Neumark, Bednarek, & Schenk, 2005) and perceived lack of support from employers, and colleagues acting as a barrier to returning to work (Nilsson, Olsson, Wennman-Larsen, Petersson, & Alexanderson, 2011).

The consequences for not returning to work can be a factor in future disorientation, as patients struggle to come to terms with the loss of work as an everyday event and search for something to fill the void left by the absence of employment (Rasmussen & Elverdam, 2008). This can result in an impaired ability to plan for the future, as financial concerns associated with unemployment may make planning for the future difficult (Verdonck-de Leeuw, van Bleek, Leemans, & de Bree, 2010). Therefore an objective of this thesis was to investigate whether or not occupational concerns could contribute to the experience of future disorientation.

It is clear that there are a number of barriers which can prevent patients with cancer from successfully returning to work following treatment for cancer. The studies above have all used semi-structured interviews focussing on specific aspects of the working lives of people with cancer, such as focussing on women who have successfully returned to work (Nilsson et al, 2011); perceived likelihood of unemployment in men newly diagnosed with prostate cancer (Bradely et al, 2005), and barriers to employment for men with head and neck cancer (Charmaz, 1994). There is a lack of understanding in the literature as to the relationship between psychosocial, physical and economic factors in the transition back into employment for cancer survivors (Mehnert, 2011), and there is a lack of focus as to how employment concerns are addressed as many patients treated for cancer will return to some form of employment (Amir, Z. Moran, Walsh, Iddenden, & Luker, 2007). Furthermore there is a lack of focus in the literature on the impact that employment

concerns can have on patient's future lives as the potential loss of income could make it difficult for patients to adapt to their lives following treatment.

## **2.6 Coping Strategies**

There are a number of definitions of coping with stressful life events such as, the transaction model which is described by Lazarus and Folkman (1984) which focuses on problem-focused coping and emotion focused coping. Problem-focused coping strategies are more likely to be utilised if, after the appraisal of a stressor one feels that something can be done to change the situation, effort is then directed at finding a solution. Emotion-focused coping on the other hand is more likely to be utilised if, after the appraisal of a stressor one feels that nothing can be done to change it, and there is a need to accept the situation, effort is then directed at reducing the emotional reaction to the stressor.

The author of this thesis feels that Leventhal's Common Sense Model (CSM), (also called the self-regulation model) (Leventhal, Meyer, & Nerenz, 1980), is better suited to explaining coping in terms of cancer as research has shown that it can highlight the difference between attenders and non-attenders at follow up appointments, which may indicate fear of recurrence (Wyer, Earll, Joseph, and Harrison, J. 2001), and patients representations of their illness has been linked to poorer outcomes in patients with cancer (Ashley et al, 2013). Fear of cancer recurrence has been identified as potentially contributing to the experience of future disorientation (Roberts & Clarke, C. L., 2009). Therefore attending behaviour at follow up clinics may be an indicator that a patient is failing to adjust to a disrupted view of their future.

According to the CSM an underlying control system accounts for responses to a health threat, this control system has three broad processes. Initially an individual will develop cognitive and emotional representations of the health threat; these will reflect the

individuals' interpretation of the threat. These can be the result of both internal and external cues such as experience of symptoms, and/or information sources. The second process involves the development of an action plan (coping strategy) which the individual believes is appropriate to the beliefs they hold. The third process in this model is the coping appraisal, which involves evaluating how effective the coping strategy was. An important aspect of the CSM is that it suggests that these three processes work in a parallel and they are dynamic in nature, with each one influenced by feedback from the other processes.

The CSM has been used to predict long-term outcomes in people with head and neck cancer (Llewellyn, McGurk & Weinman, 2007). Beliefs about the negative consequences of the illness, emotional representations, and illness identity before treatment have been associated with maladaptive coping strategies employed after treatment, such as venting, substance use, and denial. Furthermore, coping strategies were associated with both quality of life and depression, with acceptance coping being positively correlated with depression, and negatively with global health status and quality of life. In summary, what this suggests is that patients who had strong beliefs about negative consequences of their cancer before treatment were likely to adopt negative coping strategies after treatment. This in turn may lead to adverse outcomes, such as depression, and anxiety. Another study by Llewellyn, Weinman, McGurk, and Humphris (2008), found that the common sense model of illness representations was predictive of which head and neck cancer patients will develop fears of recurrence. Patients who reported high levels of denial, positive reframing, religion and planning at baseline also had higher levels of fear of recurrence at follow up, optimism was also found to be negatively related to fear of recurrence. The CSM has been developed to explain outcomes such as health related quality of life, and adherence to medication in response to illness. Previous research has shown that clear



information provision can provide patients with a map against which their actual experiences can be evaluated, which in turn can enhance behavioural and informational control (Llewellyn et al 2007).

Religious coping has been described as using cognitive and behavioural techniques which are associated with religious beliefs or spirituality when facing stressful life events (Tix and Frazier, 1998). Religious coping is characterised by praying, confession of sins, and the seeking of comfort through a relationship with God. Evidence is mixed in the literature with regards to the benefit of adopting religious coping strategies following a diagnosis of cancer. Pargament et al (1988) state that there are three different types of religious coping, not all of which are negative. The three types of religious coping are: collaborative, self-directing, and deferring. A self-reliance approach is when the patient believes in God but does not think they have any impact on the patient's recovery. This is in direct contrast to the deference approach, where the patient believes that God alone is ultimately responsible for their recovery. The third approach is a collaborative one and refers to when the patient sees themselves and God as both being responsible for their recovery. Results have shown that the adoption of either a collaborative approach or a deference approach can result in better coping. The use of religious coping strategies can have a significant impact in reducing distress or increasing illness adjustment in various cancer groups, including lung, breast, and colorectal cancer patients (Thuné-Boyle, Stygal, Keshtgar, & Newman, 2006). Therefore, it would appear that religious coping may be beneficial when trying to adapt to a cancer diagnosis, but the use of a self-reliance approach can actually lead to more negative outcomes. A study by Tarakeshwar et al (2006) investigated the role of religious coping techniques in 170 patients with advanced prostate cancer using the brief measure of religious coping. They found that poor religious coping could lead to worse psychological well-being and poorer overall quality of life.

However, no consideration was given as to why participants adopt certain types of religious coping, it may be that their religion is related to which method of coping they adopt or the severity of any symptoms they are suffering. Indeed, the authors reported that those with more physical symptoms tended to use positive coping strategies and it may be that the severity or number of symptoms is an underlying factor in which method of coping they adopt.

Other positive coping strategies have also been found to reduce stress, such as problem focussed coping strategies which can be effective at reducing stress in pregnant women (Huizink, Robles de Medina, Mulder, Visser & Buitelaar 2002) and can be an effective way of dealing with PTSD (D’Zurilla & Nezu, 2010). Furthermore, other negative coping strategies have been found to have adverse effects on outcomes following a cancer diagnosis. For example, avoidance coping strategies have been shown to have an adverse impact on mortality in those living with and beyond cancer. Deragotis, Abeloff and Melisaratos (1979), recruited 35 women with metastatic breast cancer and assessed their coping strategies, and experience of depression, and guilt and correlated these outcomes with survival time. They concluded that the use of negative coping strategies such as avoidance was associated with shorter survival, however, the researchers classed long-term survivors in this study as anyone living for more than one year. The current standard would be to class patients living for five or more years as long term survivors and were this study to be repeated it is possible that different results would be observed. Furthermore, no consideration is given to prognosis, stage at diagnosis or treatment type which may have accounted for differences in coping strategies observed in those patients who died within one year of the study. More recent studies however have found no link between coping strategies and mortality from cancer. For example, Coussong-Gelie and colleagues (2007) enrolled 75 women with breast cancer in a longitudinal study assessing anxiety, body

image, coping strategies and survival. They found that coping strategies were in no way predictive of long term survival from breast cancer. However, like the above study no consideration was given to severity, and number of symptoms which may impact on survival time and the method of coping adopted by participants (Coussong-Gelie, Bruchon-Schweitzer, Dilhyudy, & Jutland, 2007; similar results were observed by Petticrew, Bell, & Hunter (2002).

There is general consensus that the meaning attributed to stressful life experiences can aid in adjustment (Park, Edmondson, Fenster, & Blank, 2008) and studies have shown that post-traumatic growth can reduce the impact of some of the consequences of cancer and cancer treatment such as intrusive thoughts (Park, Chmielewski, & Blank, 2010), depression (Morrill et al, 2008), and perceived life threat (Cordova, Cunningham, Carlson, & Andrykowski, 2001). However, there is some debate as to whether or not meaning making can aid in adjustment to highly stressful life events such as the onset of cancer. Research evidence is inconsistent, with some studies showing that attributing meaning to cancer can be adaptive (Davis, Nolen-Hoeksema, & Larson, 1998.; Lee, V. 2008) where as others have suggested that it can result in poorer coping (Dedeli, & Kaptan, 2013). However, according to Park and colleagues (2008), the inconsistency in the research evidence may be due to a lack of distinction between meaning making as a coping process and the outcomes of this process (actual meanings made). In their study, 250 participants completed questionnaires measuring the positive reframing sub-scale of the Brief COPE survey to measure meaning making and measured actual meanings made using a number of measures of post-traumatic growth, perceived positive changes, and perceived personal meaning. They found that meaning making coping was significantly correlated to post-traumatic growth, and psychological well-being. This then suggests that attributing meaning to cancer, as long as it results in actual meanings made, can lead to post-traumatic

growth. As discussed above, post-traumatic growth can help reduce the impact of some of the negative consequences of cancer and cancer treatment. This is relevant to the study of future disorientation as it suggests that interventions which aim to facilitate post-traumatic growth may help to reduce some of the negative impacts of cancer which may be related to the experience. This also further evidences the view that the adoption of positive coping strategies has the potential to reduce the impact of future disorientation.

In summary while coping strategies would not appear to have any impact on a patient's survival from a cancer diagnosis, the evidence above suggests that it can have an impact on their adjustment to a cancer diagnosis. Adopting positive coping strategies such as acceptance and certain types of religious coping can lead to better outcomes and quality of life. The use of negative coping strategies such as venting, substance use and denial on the other hand have been linked to outcomes such as depression, anxiety and fear of recurrence and may impact on a patient's adjustment to a disrupted view of the future. Positive coping strategies on the other hand may lead to better adjustment to this disruption and reduce the negative impact of future disorientation.

## **2.7 Social Support**

Social support has been defined by P. Campbell, Wynne-Jones and Dunn (2011) as any support outside of a formal setting, such as that offered by health professionals or social services. Bert Uchino (2004) offers a broad definition of social support as including both the structures of an individual's social life such as a group of friends (structural social support) and the more explicit functions that they serve such as the provision of services, advice, or emotional support (functional social support). Most models linking the relationship between social support, and health fall into two categories termed stress related, and direct effect models. This distinction can be traced back to the work of Cohen

and Willis (1985). Cohen and Willis argued that functional support more directly meets the needs elicited by stressful events and therefore are more likely to act as stress-buffers. Structural support on the other hand is more associated with direct effect models as they tap into more general resources. This would suggest that the use of functional support can mediate the stressful impact of health problems.

Studies have shown that high functional social support is associated with better psychological well-being in a number of chronic illnesses such as rheumatoid arthritis (Fitzpatrick, Newman, Lamb, & Shipley, 1988), multiple sclerosis (McCabe, McKern, & McDonald, 2004), and chronic depression (Harris, Brown, & Robinson, 1999). Similar results have also been found in patients with cancer. Bloom and Spiegel (1984) looked at the impact of stressful situations, in this case a cancer diagnosis, and how it impacted on social functioning. They note that the onset of an illness such as cancer can prevent an individual from carrying out their usual roles and responsibilities such as going to work, and can result in changes to family roles. They wanted to investigate whether or not social support provided by ones family could buffer the impact of stressful situations on perceived social functioning, and administered a questionnaire to 86 women diagnosed with breast cancer measuring a range of variables including perceived emotional support from ones family. The results of their study demonstrated that the quality of emotional support received from one's significant others modifies the impact of stressful situations, with higher levels of emotional support being associated with a better outlook on life. Furthermore they found that less use of avoidance coping measures results in higher levels of self-reported social functioning. One limitation of this study is that although arguing that there are two dimensions of social support, social activity and emotional support, which they suggest impact on different aspects of a patient's life, they do not consider the interaction between these different aspects of social support which may impact on a

patient's adjustment following treatment for cancer. Furthermore, social support is only measured by looking at emotional support provided by one's family members and no consideration is given to wider social circles. This is important as some patients may find it difficult talking to family members about their illness for fear of worrying them (Harrison, Maguire, P., and Pitceathly, 1995).

Similar results were found in another study, focussing on women from traditionally underrepresented groups such as, minority ethnic, or women from low socio-economic backgrounds (SEB) (Bloom, Stewart, Johnston, Banks, & Fobair, 2001). Data was collected from structured interviews with 336 women, the aim of the interview was to investigate general measures of health status, measures of adjustment to illness, information about how their breast cancer was detected and their knowledge of the treatment, and socio-demographic characteristics. Social support was measured using three different constructs encompassing structural and functional social support; social network (structural), emotional support (functional), and instrumental support which included the provision of services such as providing transport and the lending of money (functional). The study highlighted that, the greater the size of a participants social network, the greater emotional and instrumental support they received, which in turn was related to better well-being. This suggests that having a large group of people to draw on will result in better well-being, but only if the support received is emotional and instrumental. One limitation of this research was that it was cross-sectional in nature and therefore no conclusions can be drawn about the impact of social support in the long-term. It is likely that levels of support, and a patient's perception of support would change over time and it would be interesting to see if this affected the impact of various consequences of cancer treatment which would add more validity to the view that social support can improve outcomes. Similar results were also found by Michael, Berkman, Colditz, Holmes, & Kawachi (2002).

Surveys were sent to 669 women who had been treated for breast cancer, measuring the frequency of their social contacts and their health related quality of life. They found social integration could significantly improve health related quality of life in cancer survivors, with those women with less social contacts scoring lower on all domains of the SF-36 compared to those who scored high for social contact. However, while stating that socially isolated women had worse outcomes than those who were not, they measured social isolation by the frequency of their social interactions. Social isolation cannot be measured by frequency of social interactions alone, the discrepancy between actual social contact, and desired level of social contact should be taken into consideration (Dykstra & De Jong-Gierveld, 1994; Peplau, 1985). This supports the theory presented by Cohen and Wills (1985) that functional support such as emotional support acts as a buffer to health related stress, whereas structured support such as social groups acts more as a general life buffer to stress.

Studies have also shown that membership of a support group can have an effect on the adverse impacts of living with and beyond cancer. Ussher et al. (2006) found that being part of a support group fostered a sense of community amongst breast cancer patients. They interviewed 93 patients who had been diagnosed with various cancers, asking them about their experiences of being a member of a cancer support group. The results showed that patients develop strong bonds with each other through the sharing of emotions and experience of being a cancer patient. Patients felt that the group provided a non-judgemental environment where they could be open and honest with each other. Positive outcomes related to being a member of a support group have also been found in patients with prostate cancer (Bottorff et al., 2008), and head and neck cancer (Vakharia, Ali, & Wang, 2007). While these studies provide evidence for the positive impact of support groups for people with cancer there are a number of limitations. Firstly, as this study was

designed to assess satisfaction with being a member of a support group then there is the potential that using focus groups as the method of data collection could result in biased results as those participants who felt that participation was beneficial may be more likely to attend focus groups. Those participants who had perhaps dropped out of the support group may have been more inclined to provide feedback in a one-on-one interview setting. Furthermore, the participants who attend support groups may do so because they do not feel that they are receiving support from other sources such as family and friends, therefore using patients who do not attend a support group as a comparison group would serve to show whether or not support groups provide any real benefit.

Goldzweig et al. (2009) found that there were sex differences in the experience of distress amongst patients living with and beyond cancer, which may be related to emotional support. A survey was sent to 231 cancer patients and their healthy spouse/partner measuring a number of items including perceived family support, adjustment to cancer, and experience of symptoms. They found that there was a significant sex differences with male patients reporting higher levels of distress than their healthy wives. Furthermore, they found that healthy male spouses also reported higher levels of distress than their wives who were patients. In relation to support the authors found that females reported higher levels of emotional support from both family and friends, regardless of whether they were they patient or the spouse of a patient suggesting that emotional support could reduce feelings of distress. These results support the findings from above that receiving emotional support can result in increased well-being. Interestingly, this seems to be the case for both patients and their spouses. Similar results were found by Harrison, J. and colleagues (1995) who asked patients to complete a checklist outlining their top ten concerns regarding their cancer. Participants were also asked how many people they felt that they could confide in with regards to their top three concerns. The authors found that 39% of males and 33% of



females reported little or no confiding of their main concern. While this suggests that females are more likely to talk about their concerns regarding cancer, the result was not significant. What is more interesting is that males were significantly more likely to have confided their main concern in just one confidant (45% compared to 25% of females), whereas females were more likely to have confided in more than one confidant which suggests that females have a larger support network than males. One limitation of this study is that over three quarters of the sample were female, and had the sample been more representative then the same difference may not have been observed. However, these results raise an important issue as studies have shown that men and women communicate differently when it comes to their health, and therefore it may be easier to recruit female participants to this kind of study.

While it is true that men and women will communicate differently with health care professionals, according to Kiss (2004) it is also important to consider that the same disease can often vary greatly in terms of symptoms, diagnosis, and treatment. For example in coronary heart disease (CHD), females often have no, or mild symptoms until they have a fatal heart attack, while angina is common in male sufferers of CHD, and is less common in females with CHD. Furthermore, the make-up of the doctor-patient dyad can also influence the communication styles of patients. Research has shown that patients will disclose more information to female physicians, in particular they will discuss more biomedical psychosocial information to female doctors than they would with male ones (Hall & Rotter, 2002). Female physicians have also been found to adopt a more patient centred approach, with low physician dominance which tends to result in higher patient satisfaction (Mast, Hall & Rotter, 2007; Street, 2002). However, other authors have found when there is no sex difference in the patient-doctor dyad (e.g. M/M – F/F) that the relationship is characterised by equality between the patient and doctor. This is evidenced

by friendly communication, greater calmness and submissiveness in voices when compared to non-same sex dyads (Sandhu, Adams, Singleton, Clarke-Carter, & Kidd, 2009). The authors of this review also found, in contrast to the findings of Hall and Roter (2002) that more biomedical and psychosocial information was provided when both patient and physician were male, rather than in any dyad with a female physician (Sandhu et al, 2009). While sex differences in communication, in a health care setting can have an impact of patient disclosure, and their satisfaction with a consultation, it has been suggested that sex differences are just one of many factors which can influence the doctor-patient relationship. Age, ethnicity and education may all play a role in the consultation process (Street, 2002).

The role of gender differences in communication is particularly relevant for the current research project as the principal investigator is a male researcher interviewing both male and female patients. Therefore the researcher has to be aware of potential differences in the content discussed by male and female participants and the potential for different lengths of interviews. With research suggesting that female patients will talk for longer with male doctors than will male patients, it is therefore possible that this difference may manifest itself in the interviews between patient and researcher. With this in mind, the work of Harrison, J. et al (1995) informed the development of the interview schedule as it looks at whom a patient confides their main concerns around cancer. This led to the inclusion of the questions relating to sources of family support and support from friends.

The above studies seem to support the theory presented by Cohen and Wills (1985) that functional support, in terms of emotional support and services offered by support groups, can act as a buffer to health related stress. Structural support on the other hand such as the size of a support network may not be as beneficial if it is not complemented by functional support. Future disorientation has been shown by Roberts and Clarke, C. L., (2009) and Maughan and Clarke, C. L., (2001) to be a distressing experience for patients and drawing

on support may be one way that a patient can minimise its impact. Therefore it is possible that the provision of functional support can reduce the impact of future disorientation. However, the majority of the studies above have adopted a cross-sectional approach when looking at support and as with many of the factors discussed in this chapter there is the potential that support can change over time. Therefore it is important to study perceived support at more than one time point if we are to understand how it impacts on various symptoms of cancer. Particular attention will be paid in the results section to the changing nature of perceived support and how this may impact on the experience of future disorientation.

Support is not only provided to patients via social networks, once primary treatment has finished patients continue to receive supportive care from clinical staff. Supportive care can be defined as the care given to improve the quality of life of patients and is designed to treat the physical and psychological symptoms of an illness such as cancer (Chen et al, 2014). Patients who have been treated for cancer receive routine follow up appointments for a period of five years for the monitoring of symptoms, and to discuss issues with their adjustment to life following treatment (Ganz, 2001; Harrison, S. et al, 2011). However, the late effects of cancer can persist for many years after follow up appointments have ended and patients can continue to encounter physical problems, poorer quality of life, financial insecurity and problems with social relationships (Foster, Wright, Hill, Hopkinson & Roffe, 2009; Ganz, 2001). A recent systematic review by Harrison, J. and colleagues identified that patients who had finished primary treatment for cancer still faced a number of unmet care needs such as problems with communication, economic issues, psychosocial problems and issues around sexuality (Harrison, J., Young, Price, Butow, & Solomon, 2009). These factors have all been identified as possible precursors to future disorientation

in the sections above and therefore suggest that current supportive care may not be sufficient at preventing the experience.

However, not all patients are dissatisfied with the supportive care they receive following treatment for cancer. Research has shown that follow-up care, delivered by specially trained clinical nurses, which address psychosocial issues, can lead to greater satisfaction with care. For example a study by Arora and colleagues (2011) looked at satisfaction with follow-up care amongst 623 patients diagnosed with colorectal cancer, leukaemia and bladder cancer who were attending follow-up appointments with a physician. Patients were administered with a survey measuring their experiences of cancer care. The study found that the majority of patients reported no problems with their supportive care, feeling that they had access to specialists when needed, that they were encouraged by their physician to ask questions relating to their care. However, 77% of patients felt that they lacked a personal relationship with their physician, and 59% reported that they had had no discussion around health promotion or recurrence prevention. Patients who had been seeing the same physician for more than two years were more likely to be satisfied with their supportive care. However, while this study states that most patients were satisfied with their supportive care, the studies above have identified a number of areas which can lead to dissatisfaction with care which were not taken into consideration in this study. Harrison J. et al (2009) identified problems with sexuality, economic concerns and communication issues which were not being addressed by current supportive care, these were not measured in this current study and therefore participants were not able to express dissatisfaction on these domains.

The above studies have highlighted that unmet care needs relating to financial concerns, communication issues, sexual functioning and psychological problems can persist for more than five years after treatment for cancer. The literature review above has highlighted that

these factors could lead to the experience of future disorientation, which therefore could also persist over time. Therefore there is a need for a conceptual framework of the experience of future disorientation which can then be used to develop interventions which would aim to reduce the experience of future disorientation by addressing these unmet care needs.

## **2.8 Research aims and outline of potential conceptual framework**

The aim of this thesis was to develop a conceptual framework that would further articulate the nature and the experience of future disorientation in adults living with and beyond cancer. The process of developing a conceptual framework has been described as iterative, constantly moving between concept and data to develop the framework (Orlikowski, 1993). According to Yossef Jabareen (2009) a conceptual framework should be informed by a multitude of data sources, comprising concepts found in the literature as well as the emerging results found by the researcher when investigating a phenomenon. Therefore, the conceptual framework which was developed as part of this thesis is presented in Chapter 8.4 and is shaped not just by the results which emerged from the data analysis but also from concepts identified in the above literature review.

The literature review outlined above led to a number of objectives which were explored in relation to the development of a conceptual framework. The objectives fell into three main categories; to explore the causes of future disorientation paying particular attention to the consequences of cancer treatment such as sexual functioning and; factors which may reduce the impact of late effects of cancer such as social support; and what the consequences of future disorientation are. The research objectives presented below will allow the researcher to compare and contrast the experience of the patients in this study in order to encapsulate the lived experience of future disorientation:

- To explore the causes of future disorientation with a focus on the consequences of cancer and treatment. Specifically this relates to fear of recurrence, identified in the literature review as a potential cause of future disorientation.
- To explore whether or not other consequences of cancer identified in the literature review, such as anxiety, depression, and functional impairment could lead to the experience of future disorientation.
- To explore whether males also experience future disorientation in relation to infertility.
- Investigate whether future disorientation leads to an inability to return to previous employment and/or an inability to look ahead and plan for the future
- To illuminate the impact of future disorientation over time.
- To explore the impact that functional support can have on the impact of future disorientation.
- To investigate the impact that positive coping strategies can have on the experience of future disorientation.

## **Chapter 3 Methodological Approaches**

### **3.1 Introduction**

Within this chapter, the development of a phenomenological approach is described together with a critical discussion of the relevance of such approach to this research. Furthermore, a critical analysis of relevant research methodologies is provided which guided the researcher to utilise an IPA approach. A detailed account of the methods adopted in this thesis is provided in the next chapter (Chapter 4).

#### **3.1.1 Research Paradigm**

A research paradigm is a set of fundamental beliefs that define how the holder views the world they inhabit (Guba and Lincoln, 1994). A paradigm encompasses, epistemology, ontology and methodology, terms which are looked at in more detail below. It is important for the research process, to make explicit which paradigmatic approach is being drawn on/guiding the research, as a clear stance helps to guide the design decisions and also helps to justify why these particular decisions have been made. The use of an established paradigm means that the researcher can build on a logical and well developed approach to research. The chosen approach should be one which corresponds to the researcher's own assumptions about the world, and their methodological preferences. The choice of a paradigmatic approach is not an entirely free one; any researcher will already have made assumptions about how the world works, and how they understand their particular research topic. While these assumptions may not be conscious decisions, they will impact on how the researcher approaches their research project (Guba & Lincoln, 1994).

Since the early 1960s there has been debate around the existence of a paradigm within the social sciences. Some social scientists argue that the goal of scientific research is to make descriptive inferences on the basis of empirical findings about the world; that all scientific

research, whether of the hard or soft sciences, should use explicit, codified and public research methods to gather and analyse data, thus allowing for assessment of reliability (Della Porta & Keating, 2008). However, not all social scientists agree with this point of view, nor do they believe that a common definition of scientific research is possible. Some social scientists believe that social science is pre-paradigmatic, according to Kuhn (2012) pre-paradigmatic means that there is no consensus on any theory, and would mean that social science is devoid of a unifying set of principles. Others still, believe that social science is non-paradigmatic, suggesting that it will never achieve a unified set of principles, instead the social world should be thought of in multiple ways, with each way being valid for specific purposes (Flyvbjerg, 2001). Finally the social world can be thought of as multi-paradigmatic, with a number of paradigms in competition with each other or ignoring each other (Della Porta & Keating, 2008).

While it is not necessary to be an expert in the field of philosophy, this researcher echoes the views of Della Porta and Keating (2008) that a basic understanding of the foundations of knowledge is an important starting point for all research. As stated above a research paradigm encompasses a number of domains, including ontology and epistemology, which will now be discussed:

Ontology is related to the form, and nature of reality, and what can be known about reality (Guba & Lincoln, 1994). Arguments about whether or not a physical world actually exists date back centuries, and in the social sciences the arguments centre on how we identify natural phenomena. There are two distinct sides to this argument. Nominalists deem that categories only exist because they have been created by humans, for example they may argue that social classes do not actually exist but are merely a creation of society. Realists on the other hand believe that the categories already exist and are just waiting to be discovered (Della Porta & Keating, 2008). Epistemology relates to what we know, and



how we can know it (Guba & Lincoln, 1994). It is distinct from ‘belief’ in that it requires justification for saying that something is so, if we are to potentially convince others (Everson, 1990). Whereas in the natural sciences they have shared standards of evidence, argument, and logic, this is not so in the social sciences. Some social scientists call for objective evidence as in the natural sciences, whilst others insist that other forms of knowledge are possible. For example, social scientists may discard a common held belief as myth if it cannot be backed up by empirical evidence, anthropologists on the other hand may reject this stance as myths and beliefs are as valid a form of data as any other (Della Porta & Keating, 2008).

It could be argued that the realist approach to knowledge used in the natural sciences, whereby categories already exist in the world and are waiting to be discovered is not appropriate for social research which focusses on the experience of individuals. The author of this thesis does not believe that human experience is observable or categorical, and prescribes to the view of Carr and Kemmis (1986) that the experience of an individual is unique and only exists in the context of their experience of it. The role of the researcher is to try and understand what that experience means to an individual. By comparing and contrasting the experiences of individuals, the researcher can start to develop a bigger picture of what the experience means to a homogenous group, which is more sophisticated than any of the individual accounts. Given my ontological position outlined above, it is felt that the research questions could best be answered using a constructivist approach, the reason for which is detailed below.

### *Constructivist Paradigm*

As discussed earlier, each research paradigm is made up of a distinct set of beliefs that consist of: ontology - what we know about the world; epistemology - how we know what

we know about the world and methodology - the tools we use to discover things about the world (Lincoln, Lynham, & Guba, 2011). The position taken for each within a constructivist paradigm is described here: Constructivism adopts a relativist ontology which assumes that numerous realities exist, although many 'realities' may be shared between individuals and cultures. Realities are dependent on the individual persons or groups which hold them and constructions are not seen as more or less true, but merely more or less sophisticated (Guba & Lincoln, 1994). The epistemology of a constructivist paradigm is subjectivist and transactional (Guba & Lincoln, 1994) where the understanding of a phenomenon is created by interactions between the researcher and the research participants.

This means that a researcher can never truly understand the experience of their participant, and that the data produced in an interview is the researcher's attempt to understand a phenomenon from the participants' perspectives. The methodology chosen to go along with a constructivist paradigm should be hermeneutic and dialectical (Gubba & Lincoln, 1994; Appleton, J. & King, 1997). This is because of the variable and individual nature of the social constructions, which suggests that individual constructions can be elicited and refined only through interaction between, and among, investigator and respondents (Lincoln, 1992). These varying constructions are interpreted using conventional hermeneutic techniques, and are compared and contrasted through a dialectical interchange (Guba & Lincoln, 1994). This involves the process of looking for common themes amongst participants, and comparing and contrasting their accounts, thus allowing the researcher to form an overall description of the experience. In essence, the transcripts are talking to each other. The final aim is to create a new construction, which is more refined and sophisticated than any of the original constructions which helped to form it, (Eisenhart, 1988) this is made possible by the dialectical interchange. A constructivist approach lends

itself to methodologies such as interpretative phenomenological analysis (IPA) where the researcher engages with the participants to try and gain a deep understanding of their experience of a phenomenon (dialectic interchange). Through the interpretation (hermeneutics) of each individual participant's data, the researcher can reconstruct the phenomenon and create a new construction, which better depicts the experience of the group as a whole.

There has been a growing body of research using constructivism as an approach to qualitative enquiry. This however, has created its own problem as this rising popularity has seen the approach become expansive and vague, meaning it may have become too diverse to accurately define. It is therefore better perhaps, to think of constructivism as a myriad of research efforts, each with diverse, but often overlapping, philosophical, theoretical, methodological, and empirical underpinnings (Holstein & Gubrium, 2011).

### **3.2 Development of Phenomenological and Interpretative thinking**

Phenomenology can be described as a philosophy that investigates individual experiences from a first person point of view (Romdenh-Romluc, 2011). The interests and emphasises of phenomenologists can be varied. However, they have all tended towards one interest in particular, thinking about what human experience is like, in all of its various aspects, but especially in terms of things that matter to us, and make up our lived world (Smith, J. A., et al, 2009). The development of phenomenological thinking can be traced back to the work of a number of key individuals, including Husserl, Heidegger, Merleau-Ponty, and Sartre.

The founding principle of phenomenological inquiry is that experience should be studied the way it occurs, and in its own terms. Husserl believed that in order to illuminate an experience, it is essential to gain an understanding of what an experience is like at an individual level (Husserl, 1927). In other philosophical standpoints such as positivism,

there is a tendency towards order and a need to fit ‘things’ within our current categorization system (Della Porta & Keating, 2008). Phenomenology suggests that focus should be on each individual thing in its own right. While each individual’s experience of a particular phenomenon will be unique in some way, these experiences will also have something in common. Therefore, phenomenology allows the researcher to use these individual experiences to gain a fuller understanding of the collective experience (Smith, J. A., et al., 2009).

Heidegger’s work has been described as “a move away from the transcendental project, and to set out the beginnings of the hermeneutic and existential emphases in phenomenological philosophy” (Smith, J. A., et al., 2009, pp16). Heidegger questioned whether it was possible to gain an understanding of someone else’s experience without taking an interpretative stance (Heidegger, 1962). Heidegger is more concerned with the ontological question of existence itself, and with the practical activities and relationships which we engage in, and through which the world is made meaningful. He concluded that one cannot choose to move outwards from some inner world to take up a relationship with the various somatic and semantic objects that make up our world, because relatedness-to-the-world is a fundamental part of our constitution (Larkin, Watts, & Clifton, 2006). The key ideas to take from Heidegger are firstly that human beings can be conceived of as propelled into a world of objects, relationships, and language. Secondly, our being-in-the-world is always perspectival, always temporal, and always with regards to something. Consequently, the interpretation of people’s meaning-making activities is central to phenomenological enquiry in psychology (Smith, J. A. et al., 2009).

Merleau-Ponty concentrates much of his work on the embodied nature of our relationship with the world – “The body, no longer conceived as an object in the world, but as our means of communicating with it” (Merleau-Ponty, 1962, p. 92). For example, if your hand

reaches out and touches something, this represents the meeting point of the self and the world; it draws you to the world in the act of touching (Smith, J. A. et al., 2009). Merleau-Ponty's concerns with subjectivity and embodiment come together when thinking about how we see other people. Our perception of them develops from an inner perspective, and thus our relation to others always begins from a position of difference. This means that while we can observe and experience empathy for one another, we can never wholly share the other's experience as this belongs to their inner perspective. For qualitative researchers and for IPA researchers in particular, this view that the body shapes the fundamental character of our knowing about the world is critical (Smith, J. A., et al., 2009).

Phenomenology was further developed by Sartre who famously expressed that existence precedes essence and that the self is not a pre-existing unity to be found, but rather a continuous project to be unravelled (Sartre, 2012). Another key concept discussed by Sartre was the concept of nothingness, which relates to his focus on what we will be rather than what we are. Sartre felt that things which were not present are as important as those that are, in defining us and how we see the world (Smith, J. A., et al., 2009). Sartre expands Heidegger's emphasis on the worldliness of experience by developing the point in the context of personal and social relationships, so that we are better able to envision our experiences as dependent upon the absence, and presence of our interpersonal relationships (Smith, J. A. et al., 2009).

In terms of my research project; understanding phenomenology, and the importance of focussing on experience and perception, as highlighted by Husserl, and how individual experiences can be compared and contrasted to gain an overall understanding of an experience helped to shape the approach to my data analysis. The phenomenon explored within this research is something which is not fully understood amongst people living with and beyond cancer, future disorientation. Therefore, it was felt that it was important to

look at individual experiences of male and female participants, and participants with different tumour types so as to compare and contrast their experiences. This would allow for the development of a new construction of future disorientation borne out of the individual experiences of the research participants.

While Husserl advocated studying the experience of individuals, so as to illuminate that experience for others, the work of Heidegger, Merleau-Ponty, and Sartre points to the role of interpretation in research and how we can never really know the experience of another person. If one can never hope to understand the experience of another person, then a researcher is always relying on their own interpretations of the data generated in their interactions with a participant. Furthermore, the work of Merleau-Ponty (1962) highlights that the role of the researcher, and the participant in understanding a phenomenon and supports the multi-reality ontology of constructivism. Therefore, when a researcher and participant discuss a phenomenon, it is understood only in the context of that interaction. One must then study a number of realities in order to build up an overall understanding, or construction of a phenomenon. As stated previously, this research sought to build up a picture of the nature and experience of future disorientation by comparing and contrasting individual accounts of future disorientation. The work of Heidegger (1962) and Merleau-Ponty (1962) would suggest that analysing individual accounts before building up an overall picture would be the best way to illuminate the experience of future disorientation. As Heidegger suggested that no one can step outside of their lived experience, then it stands to reason that no one can step into another lived experience. Therefore, any researcher trying to understand the lived experience of others does so through their own world perspective. The subsequent meaning they make of other people's lives is always their interpretation of another person's lived experience. Therefore, looking at the work of Husserl and Heidegger, it was concluded that the best way to understand a common

phenomenon was to gain an understanding of the different experiences of individuals living with and beyond cancer. Through interpretations of these individual experiences, a picture could be built up of what future disorientation means to people living with and beyond cancer.

### **3.3 Critical analysis of potential qualitative methodologies**

The researcher's philosophical standpoint must be congruent with a constructivist paradigm, and the methodology used to analyse the data must therefore align itself with this paradigmatic approach. A number of possible methodologies were considered, and three were identified which aligned with the researchers philosophical stance. Interpretative phenomenological analysis, thematic analysis, and a constructivist approach to grounded theory are ontologically similar (Spencer, Ritchie, & O'Connor, 2003). In the following pages a critical analysis of each approach is given in relation to the present research, which led to the decision to adopt an IPA approach.

#### **3.3.1 Interpretative Phenomenological Analysis**

IPA was developed by J. A. Smith as an iterative process during the 1990s and early 2000s (1996; 2009). It was developed as an approach which would allow researchers to unravel the meanings contained in participant's experience of a phenomenon through a process of interpretative engagement with the transcripts (Willig, 2008) and has been used extensively in Health Psychology research (Fade, 2004; Flowers, et al, 2006; Larkin et al, 2006; Wyer et al, 2001). In particular IPA research is concerned with what happens when everyday life takes on a particular significance which may be caused by an important life event (Smith, J. A., et al, 2009). Thus when individuals reflect on an experience of a major life event, such as being diagnosed with cancer, they begin to reflect on the significance of the event. In IPA research, the goal of the researcher is to attempt to make sense of the participant's

reflections (Clarke, Channine, 2009). With this in mind it is important to acknowledge the role of the researcher within IPA, as the researcher is actively engaged in the research with their attempt to make sense of the participants attempt to make sense of their experience. IPA is subjective in nature and researchers using this approach are encouraged to recognise that the experience of each individual is unique. The goal of IPA studies is to reveal something of the experience of each participant within the study, and as such part of the study may reveal the similarities and differences between each participant. Once each participant account has been analysed then it is possible to move onto more general claims about the group of participants as a whole. This is in keeping with a constructivist paradigm, with each construct adding something to the research, with the goal at the end of the research to have created a new construction from the sum of the parts, which is more sophisticated than any of the individual constructions from which it developed (Gubba & Lincoln, 1994).

As stated earlier, IPA is a relatively new methodology when compared to other qualitative approaches, and is unlike grounded theory and thematic analysis, which have a number of approaches to them which have been advocated over the years. In their book, J. A. Smith et al. (2009) outlined a series of steps to be taken when conducting IPA research. However, they stress that researchers should be flexible in their implementation of these steps and accept that they may not all be appropriate for every research study. It is important to note that in IPA the research questions and the subsequent interview topics explored with participants are not theory-driven. It is however, recommended to conduct a literature review, which can help to identify a gap which the research question can address. For example, for this particular study two key gaps in the literature were identified concerning future disorientation, which this research is attempting to bridge; namely that



no studies had yet been conducted exploring future disorientation in males living with and beyond cancer, and that none so far had followed patients up after the initial interview.

An important aspect, is that IPA recognises that the researcher has an active role to play in the research, and as such, it is important to put your pre-conceptions to one side, which is achieved through bracketing, something which is discussed in more detail later in this chapter. This is particularly important at the data analysis phase, where once the researcher has analysed one interview, they will have already begun to form ideas about potential themes which may then influence analysis of subsequent interviews. Data collection in IPA is particularly suited to detailed accounts of an individual's experiences, and as such it has a preference for semi-structured interviews, however, other sources of data such as research journals may also be useful (Smith, J. A. et al, 2009). An interview schedule is used to facilitate an interaction which allows the participant to answer a research question without directly asking the question. This is achieved by preparing questions which are open and expansive and the participant should be encouraged to talk at length. In phrasing particular questions, it is important to choose formulations which do not make too many assumptions about the participant's experiences or concerns, or lead them towards a particular answer. Probing can be used after a question has been answered to allow the researcher to explore a participant's experience further (Smith, J. A. et al, 2009).

IPA analysis follows a similar pattern to many other qualitative methodologies, in that it starts with reading the transcripts and making initial notes. These notes are then turned into emergent themes which group together similar and contrasting excerpts from the data. These themes are then grouped into super-ordinate themes which group similar emergent themes together.

While IPA has been chosen as the appropriate methodology for this study, it is important at this stage to recognise the limitations of this methodology. One of the major limitations is its interpretative nature, as it is the role of the researcher to interpret what the participants are saying this raises issues of validity. However, there are steps which can be taken to ensure validity and transparency within IPA research, (discussed in Chapter - 4.7). Another issue that arises from IPA is that it is recommended that each case should be analysed separately from all others and the data from one case should not influence subsequent analysis. However, it can be argued that it is virtually impossible to completely set aside your knowledge of previous interviews, due to the fact that you have immersed yourself in the data (Smith, J. A. et al., 2009). The exception to this would be if you are part of a research team and different members of the team are responsible for data collection and analysis, then it is possible for the analysis to be uncontaminated by previous knowledge. However, with the study which forms the basis for this thesis, there is only one researcher, myself, who is responsible for all aspects of the data collection and analysis, and it is important to acknowledge that my intimate knowledge of cases may have influenced my analysis of subsequent cases. A way of minimising this is to utilise bracketing as discussed previously. Bracketing is originally rooted in mathematics whereby when working on a mathematical equation you would bracket parts of the equation to keep them separate from each other, while each bracketed part of the equation can be seen as distinct, they still relate to each other, and together make up the whole equation (Husserl, 1927). In terms of qualitative research, each transcript is a bracket, and the research questions form the equation to be solved. Bracketing would then mean analysing each transcript in its own right before combining the results of each bracket to answer the overall equation. However, this is not always something which is easy to accomplish as one becomes so immersed in the data it can be difficult to set your knowledge of previous transcripts behind when moving on to the next one. Therefore, the

researcher acknowledges that their exposure to, and judgements made of, each transcribed interview will have in some way influenced the analysis of subsequent transcripts. As discussed in the data analysis section of the next chapter (Chapter 4.7), being aware of this allowed the researcher to recognise this was an issue and take steps to minimise any bias it may have caused.

IPA has also been criticised for a failure to provide causal explanations of phenomenon (Willig, 2008), however it can also be argued that the purpose of qualitative research is not to provide causal explanations (Maxwell, 2005). Instead IPA is a method which can contribute to the existing knowledge of a phenomenon by eliciting an understanding of what the phenomenon means to the participants (Clarke, Chanine, 2009).

IPA has been chosen as the methodology to analyse the data in this research project for a number of reasons. Firstly, if we refer back to the research question, the primary aim of this research is to develop a framework of the experience of future disorientation in adults living with and beyond cancer. One of the core aims of IPA is to provide a detailed account of an individual's experience; this reflects the ontological position of the researcher that each individual's experience is unique to them. IPA allows the researcher to analyse each participant individually and look at what that experience means to them. Once each participant has been analysed, the researcher can start to look for differences and similarities in these accounts and build up a picture of what the experience means to the group of participants in general (Smith, J. A., et al., 2009). This methodology reflects the constructivist paradigm which looks to build sophisticated group constructions from the individual constructions of participants (Gubba & Lincoln, 1994).

### **3.3.2 Grounded Theory**

While it was decided not to utilise grounded theory as the methodology for this current research project, it does have a number of advantages which make it useful for research within a constructivist paradigm. Grounded Theory will be outlined below before discussion moves onto discuss why this methodology was rejected in favour of Interpretative Phenomenological Analysis.

Grounded Theory was developed by Glaser and Strauss as a method of systematically generating theory from data, which is gathered and analysed in a systematic way (Wertz et al., 2011). Theories evolve during the research process, doing so through continuous interplay between analysis and data collection (Strauss & Corbin as cited in (Denzin & Lincoln, 1998)). Theory may be generated during the course of the research, or previously generated theories may be elaborated and modified in future research as incoming data are meticulously played against them (Della Porting & Keating, 2008). One of the major differences between phenomenological research and grounded theory is where phenomenological research is concerned with assigning a common meaning to experience, through the study of several individuals; grounded theory is primarily intended to discover a theory that explains a concept, process, or interaction among individuals (Miller & Salkind, 2002).

According to Miller and Salkind (2002), there are three discernible variants to conducting grounded theory research, the systematic procedure, the emerging design, and the constructivist approach. The systematic design approach is widely used in social science research, and was developed by Strauss and Corbin (1990) building upon the original concepts of Glaser and Strauss (1967). This approach advocates that research should adhere to the following principles: the use of open, axial, and selective coding, and the development of a logic paradigm or a visual picture of how the theory has been generated.

Open coding is similar to the process of initial noting and recognising emerging themes in IPA, as it involves searching the data for a number of themes, and within these themes there will be a number of related sub-themes. Axial coding on the other hand involves selecting one of the themes and placing it in the centre of a document, or on a table, and moving other themes around that fit with this theme. Again, this bears resemblance to the process of identifying super-ordinate themes in IPA. Procedurally, this involves integrating and refining the theory through techniques such as, writing out the story line that interconnects the categories, and sorting through personal memos about theoretical ideas. In a story line the researcher might examine how certain factors influence the phenomenon leading to the use of specific strategies with certain outcomes (Miller and Salkind, 2002).

The emerging design approach was developed as a critique of the systematic design approach by Glaser (1992), who had initially worked with Strauss in developing grounded theory (Glaser and Strauss, 1967). Emerging grounded theory puts less emphasis on the heavily structured technique of the systematic approach. Instead the theory emerges from the data in a structured way using pre-set, specific categories. According to Glaser, the point of grounded theory research is for the author to explain a basic social process, this explanation involves the constant comparative coding procedures for comparing incident to incident and incident to category, as well as category to category (Miller & Salkind, 2002).

The constructivist design has been articulated by Kathy Charmaz as a philosophical position between the positivist stance of Glaser, Strauss, and Corbin and the postmodern researchers (Charmaz, 2011). This methodology places more emphasis on the subjective meaning attributed to participants in a study. It can be seen as more phenomenological than the other two methods of conducting grounded theory research described above, as it is interested in the views, values, and beliefs of individuals rather than in gathering facts

and describing acts (Miller & Salkind, 2002). In terms of data collection, different techniques may be used but most research primarily uses 20-30 minute interviews, recruitment of participants will continue until no new data emerges from the interviews (data saturation) (Denzin & Lincoln, 1998).

After careful consideration it was decided that a grounded theory approach was not the best way to address the aims of this particular research. The ontological position of the researcher assumes that the world is subjective. Therefore it is assumed that experience only exists in the minds of those who have experienced it and no one else can step into this lived experience. Constructivism also acknowledges the active role of the researcher, and we can therefore discount many of the approaches used within grounded theory which assumes that the researcher is neutral and takes an objectivist approach to research (Charmaz, 2011). However, there are differing approaches within grounded theory and not all of them are objective in nature. Constructivist grounded theory adopts a subjective approach with the focus more on an interpretative understanding than on theoretical generalizations. It also recognises that the researcher is inherently part of the research and their views and preconceptions will influence the research process (Charmaz, 2011). While this is in keeping with the ontological position of the researcher, it is still felt that a constructivist grounded theory approach is not best suited to answering the research questions. This is because constructivist grounded theory looks to produce a theory which can be generalised to the group as a whole, using individual accounts as evidence for the theoretical claim (Smith, J. A., et al., 2009). However, while IPA utilizes a similar method in using individual experiences to build up a deeper understanding it was felt that IPA allows for more focus to be paid to converging accounts as well as consensus. This research is exploring whether or not future disorientation is experienced by male and female participants and is looking to understand the world of those participants who do not

experience future disorientation as well as those who do. An IPA approach allows more scope to explore this area fully.

### **3.3.3 Thematic analysis**

Like grounded theory there are various ways in which a thematic analysis research project can be conducted. Thematic analysis can be either inductive or theoretical, and themes can be identified by searching for semantic or latent themes. Thematic analysis is a diverse methodology which can fit within a number of different paradigms such as essentialist, realist or constructionist (Braun & Clarke, V. 2006). However, there are a number of reasons why it is not suitable for addressing the current research aim.

Unlike other methodologies such as interpretative phenomenological analysis, thematic analysis suffered from a lack of guidance on how to carry out a study from beginning to end. This however changed with the publication of the paper ‘using thematic analysis in psychology’ (Braun & Clarke, V. 2006). There are a number of different methods which can be employed when conducting a thematic analysis study, these are discussed below.

Inductive versus Theoretical Thematic Analysis - Inductive thematic analysis is a bottom up approach where themes are identified which are strongly linked to the data themselves (Braun & Clarke, V. 2006). Within this method if the data was collected specifically for the research then the themes identified may have little relationship with the specific questions asked. Furthermore, they would not be driven by the researcher’s theoretical interest in the research topic. Inductive analysis is therefore a process of coding the data without trying to fit it into a pre-existing coding framework and themes should not be driven by the researcher’s pre-conceptions (Bishop and Yardley, 2007). Theoretical thematic analysis on the other hand is driven by the researcher’s theoretical interest in the area and is more researcher-driven. This kind of analysis produces a detailed analysis of a

certain aspect of the data as opposed to the rich description of the data provided by inductive analysis. The decision between an inductive or theoretical approach maps onto what the researcher is coding their data for, this can either be coded for a specific research question (theoretical) or the research question can be left to evolve out of the data (inductive).

Semantic versus Latent Themes - Another decision surrounds what level to identify themes at, this can be done on either a semantic level or a latent level. With a semantic approach, themes are identified within the explicit or surface meanings of the data, with the analyst not looking for any meaning beyond what is presented in the data itself. Preferably the analytic process would involve a progression from the descriptive, showing patterns in the semantic data, to interpretative, where an attempt is made to theorise the significance of the patterns observed and what they might mean to the participants (Braun & Clarke, V. 2006). At the latent level of analysis the aim is to go beyond the semantic content within the data, and start to identify or examine the underlying ideas, assumptions, and conceptualisations that are theorised as shaping or informing the semantic content (Burr, 1995). Thus a latent thematic analysis would lend itself to a constructionist paradigm as it begins to look at the underlying ideas and assumptions of the data. The researcher can then begin to unpick what an experience means to the participant and themes develop out of the researcher's interpretation of the data.

While thematic analysis fits within a constructivist paradigm and involves some level of interpretation, there are a number of issues with this methodology which make it inappropriate for this current research. Firstly, one of the key components of thematic analysis is that it looks for themes across the entire data set (Joffe & Yardley, 2004). Although this can be useful, this particular study is exploring an under researched area. In particular the experiences of male participants in this area has not been researched before,



therefore an in-depth analysis looking for themes on an individual, rather than a group level, is better suited to addressing the research objectives. Thematic analysis tends to place emphasis on the prevalence of themes within the data set (Joffe & Yardley, 2004). This does not confer with the ontological position of the researcher who believes that the experience of an individual is unique. While individual accounts can be compared and contrasted to build more sophisticated accounts of an experience, attention should also be paid to the convergence and differences of each account. While it is acknowledged that there is no set method to how prevalent something must be to constitute a theme within thematic analysis (Smith, B. & Sparkes, 2012) it is stated by Braun & Clarke, V., (2006) that ideally there will be a number of instance of a theme across a data set. This links into the process of identifying themes on a global rather than a local scale, as it may be that an important theme is only discussed by one participant and this would be missed by thematic analysis.

## **Chapter 4 – Methods**

Once it had been decided that the methodological approach to the study would be Interpretative Phenomenological Analysis, the next stage was to design the methods which would be used to carry out the research. The starting point for this was to decide the best way to recruit participants to the study, and the best way to collect data from them in order to explore the research aims and objectives.

Given that participants who have been treated for cancer will attend follow up appointments at hospital for up to five years after treatment, it was felt that the best way to recruit participants would be through the NHS. This meant that one of the first steps in the study would be to recruit gatekeepers in the form of clinical nurse specialists (CNS) who would make initial contact with the participants. This is explained in more detail later in this chapter, (Section 4.3). After deciding on the patient population from which participants would be recruited, the next step was to decide on a method of data collection. Following the recommendation of J. A. Smith et al (2009) it was decided that using semi-structured interviews would enable the collection of rich data from each participant that allows them to speak freely about their experience. What follows in this chapter is a step by step description of how the research project was carried out, from the design stage and the development of the interview schedule, to the recruitment of participants and the design of the semi-structured interviews and analysis of the collected data.

### **4.1 Design**

This research was performed using a convenience sampling technique. Given the aims of this thesis it was felt that the most appropriate approach to this research would be to take a longitudinal qualitative approach.

## **4.2 Ethical Approval**

Once the research aims had been defined, the interview schedule had been designed and a source of potential participants had been identified the next stage in this study was to seek ethical approval. This came firstly from Northumbria University school ethics committee, and as the target population were being recruited from an NHS site, NHS ethics committee approval was also sought.

### **4.2.1 Departmental Ethical Approval**

Departmental ethical approval involved submitting a detailed research protocol to the school research ethics subcommittee. This protocol outlined the project and background research in detail and outlined potential ethical considerations for the project. It was noted that there would be minimal risk of harm involved for the patients, but due to the sensitive nature of the interviews it is possible that some patients may become distressed. With this in mind participants are informed in the information sheet that if they become distressed then they may have to be referred back to their CNS. Furthermore in order to minimise burden in terms of travel, all participants are offered the chance to have the interview conducted in their homes. If the patient was unwilling to have a home interview, then a room could be used in the designated hospital in England. The protocol was submitted in March 2011, on the 15<sup>th</sup> of April the research ethics subcommittee requested some minor information before accepting the study. Approval was granted for the study by the research ethics subcommittee on the 25<sup>th</sup> of May 2011.

### **4.2.2 NHS Ethical Approval**

NHS Ethical Approval was applied for on the 13<sup>th</sup> of July 2011. This involved submitting an IRAS form on the NHS research website along with a copy of all relevant

documentation such as interview schedules, information sheets and consent forms. In conjunction with this NHS R&D approval was sought along with a letter of access allowing the researcher to contact NHS patients who had been identified by the CNS. Gateshead Health NHS Foundation Trust agreed to act as sponsor for this study.

#### **4.3 Participant Recruitment**

Participants for this study were recruited using a convenience sampling technique. Patients attending a hospital in the North East of England for a follow up appointment with a CNS were asked to participate in this study. In accordance with J. A. Smith et al (2009 pp48-51) a small homogenous group of eight participants was sought for this study. Recruiting too many patients for an IPA study can be problematic and detract from the gathering of rich data, and it is recommended that no more than ten participants be recruited for an IPA study. It may be argued that the sample recruited for this study was heterogeneous as both men and women were recruited with various cancer types. However, it could also be argued that no group is ever truly homogeneous as there will always be individual differences within a group. Therefore in the context of this study homogeneity relates to any adult living with and beyond cancer. Scope for this broad definition of homogeneity was set by one of the authors of the IPA textbook which outlines how to carry out an IPA study (Smith, J. A. et al, 2009), as Flowers et al (2006) recruited a sample of HIV positive males and females as a homogenous sample. Many qualitative studies will employ purposive sampling techniques where a framework may be used to ensure that participants meet certain characteristics and is designed to ensure that the research question is answered (Marshall, 1996). However, Lucas (2014) would argue that a key criticism of purposive sampling is that the social world is 'lumpy'. The social world has an infinite number of factors of unknown power which need to be considered. No matter how much information a researcher has about their sample, distortion is still possible because the research lacks

sufficient power and knowledge to counter these infinite factors. Lucas therefore argues that purposive sample actually ensures that a researcher is 'unable' to validly answer their research questions (Lucas, 2014). Purposive sampling is not needed to address the aim of this thesis; instead a target population should be defined (adults living with and beyond cancer) and appropriate participants should be approached within this population who will provide rich, idiographic accounts of their experiences which will shape the development of the conceptual framework. Initial contact was made with the nurses in November 2011 and each CNS was given a recruitment pack which contained the information sheet for the study (see Appendix E), and an invitation letter for the study (appendices B and C). The CNSs were asked to discuss the study with participants who were eligible and to pass on the information sheets and invitation letters. In December 2011, four participants were identified by the colorectal CNS as potential participants for the study, two males and two females. The participants were contacted and all agreed to be interviewed in their homes between December 27<sup>th</sup> 2011 and January 25<sup>th</sup> 2012. After recruiting the initial cohort of participants in December 2011, a number of reminder e-mails and phone calls were made to the senior CNS to ask her to remind the other CNSs about the study. A further two women were recruited in June 2012 from the gynaecological CNS, again both participants were contacted and agreed to be interviewed in a room within the designated hospital between the 16<sup>th</sup> of July and 2<sup>nd</sup> of August 2012. The final two male participants were recruited from the colorectal CNS, one participant opted to be interviewed at home, with the other asking to be interviewed within the designated hospital room. These interviews took place on the 7<sup>th</sup> of September and the 3<sup>rd</sup> of October 2012.

The procedure for recruitment to the second stage of interviews was slightly different as initial contact had already been made with the participants. Second interviews were scheduled to take place 6 months after the initial interviews, therefore after 5 months the

CNSs were contacted to ask if they were still happy for their patients to take part in the study. If the CNSs felt that their patients were too unwell, or not in the right frame of mind to take part, then they would request that their participants be excluded from this stage of the data collection. All eight participants were deemed able to continue with the study and the researcher began contacting participants from the first cohort in late May to early June 2012 to arrange interviews. Contact was made with three of the participants and interviews were arranged to take place between the 31<sup>st</sup> of July and the 4<sup>th</sup> of October 2012. One participant could not be contacted and after several phone calls a reminder letter was sent asking him to contact the researcher if they still wished to take part in the second interview. The participant never made contact and was therefore not included in the second round of interviews. Contact was made with the second cohort of participants in the middle of February 2013 and four interviews were arranged to take place on the 25<sup>th</sup> and the 28<sup>th</sup> of February 2013. This concluded the data collection phase of this study.

**Table (4.1) Interview Flow**

<b>Participant</b>	<b>1<sup>st</sup> Interview</b>	<b>2<sup>nd</sup> Interview</b>
Sarah	27 <sup>st</sup> December 2011	31 <sup>st</sup> July 2012
Geoff	28 <sup>st</sup> December 2011	3 <sup>rd</sup> October 2012
Paul	10 <sup>th</sup> January 2012	<i>Participant could not be contacted</i>
Lindsay	25 <sup>th</sup> January 2012	7 <sup>th</sup> September 2012
Lucy	16 <sup>th</sup> July 2012	25 <sup>th</sup> February 2013
Rachel	2 <sup>nd</sup> August 2012	25 <sup>th</sup> February 2013

**Table (4.1) Continued**

John	7 <sup>th</sup> August 2012	28 <sup>th</sup> February 2013
Rob	3 <sup>rd</sup> September 2012	28 <sup>th</sup> February 2013

The sample consisted of the first four female patients and the first four male patients identified by the CNSs who agreed to take part in the study. This resulted in a somewhat skewed sample as six participants recruited had been treated for colorectal cancer, and two for gynaecological cancer. Table 4.2 below outlines the characteristics of the sample. As can be seen there is a wide spread of employment status, age, time since diagnosis, previous diagnosis of cancer, and different treatment types which should allow this study to see what factors may influence experience of future disorientation within the sample. This enabled consideration of how employment status impacts on participants' experience future disorientation, which is addressed in Chapter 7. Furthermore, the time since finishing treatment varied across the participants from 6 months post treatment to 4 years post treatment, thus enabling a look at the impact of time since finishing treatment. Finally, of the participants recruited there were a mixture of those who had been diagnosed with cancer on a previous occasion and others who had been diagnosed only once, allowing an exploration of differences in the experience of future disorientation in those participants who have had more than one cancer diagnosis.

**Table (4.2) Sample characteristics**

Alias	Age	Tumour	Diagnosed (Time since diagnosis when interviewed)	Employed	Previous cancer	Treatment	Stage at diagnosis
John	44	Colorectal (with Stoma)	2012 (< 1 year)	Full Time Employment	No	Surgery	T2
Paul	65	Colorectal (no Stoma)	2009 (3 years)	Seasonal Employment	Yes	Surgery	Unknown
Geoff	50	Colorectal (no Stoma)	2008 (4 years)	Full Time Employment	No	Surgery	Unknown
Rob	60	Colorectal (no Stoma)	2011 (1 year)	Retired	No	Surgery + Chemo	Unknown
Rachel	43	Ovarian	2010 (2 years)	Full time Employment	No	Surgery	Unknown
Lucy	57	Cervical	2011 (1 year)	Voluntary	Yes	Surgery + Chemo	Unknown
Lindsay	68	Colorectal (no Stoma)	2011 (1 year)	Retired	Yes	Surgery	Unknown
Sarah	72	Colorectal (no Stoma)	2010 (2 years)	Retired	No	Surgery	T3 N1



#### **4.4 Creating a schedule for semi-structured interviews**

As stated in the previous chapter, the preferred method of data collection in IPA is semi-structured interviews, with the use of open ended expansive questions designed to facilitate an interaction which allows the participant to talk about their experience. While semi-structured interviews were chosen for this particular study, any method of data collection which provides a rich and detailed first person account of experiences could be used within IPA (Smith, J. A. et al., 2009). For example, IPA studies often use unstructured interviews which are participant led and do not follow a standard set of questions (Clare, Rowlands, Bruce, Surr & Downs, 2008). While unstructured interviews are often used for an exploratory study such as this, the researcher had never conducted a qualitative interview before and it was felt that they would benefit from some structure to the interviews to ensure that they fully captured the patients' experience. Furthermore, the literature review had highlighted specific areas relating to the nature and experience of future disorientation which this research aimed to explore in relation to the conceptual framework. It was felt that a semi-structured approach would allow for appropriate prompts to be included in the interview schedule allowing for a fuller exploration of future disorientation. Recently IPA researchers have utilised computer-mediated data collection methods such as e-mail correspondence (Murray, 2004). While this has benefits such as giving the participant time to think about their responses to questions, and instant transcription, it has the potential of excluding patients who are not computer literate. Furthermore, the researcher has no control over how long it takes for participants to respond and they are not on hand to clarify questions that participants may have which may result in data which is poor in quality. While utilising an electronic method of data collection would have allowed for a larger sample to be recruited due to the reduced time it would have taken to transcribe and analyse the interviews, it was felt that this method would have excluded participants who

did not have access to a computer or who did not feel comfortable corresponding by e-mail. Furthermore, as we wanted to keep our sample size within the IPA recommended size of between six and ten participants then it was felt that this method would not have benefitted the analysis process for this particular research.

The need for an open and expansive interview schedule which allows the participant to talk about their experience was taken into consideration when designing the interview schedule for this current research. The interview schedule can be seen in Appendix H. It is important to note that the interview schedule should be flexible, and often the asking of additional questions will be necessary to gain more in-depth information about an area that the participant has discussed.

With this in mind, a semi-structured interview schedule was prepared for this study. It includes eight open questions designed to get the participant talking about the impact cancer has had on their lives, and any possible implications for their ability to plan for the future. As part of the preparation for the interview schedule some questionnaires designed to measure psychological well-being in people living with and beyond cancer were consulted, such as the Impact of Cancer Scale (Zebrack B.J., Ganz, Bernaards, Peterson, & Abraham, 2006), and the Warwick and Edinburgh Mental Well-Being Scale. These can be seen in Appendix F and Appendix G. This helped inform the interview schedule and get participants talking about their general feelings of well-being. Questions ranged from ‘Please could you talk about your cancer journey?’ to ‘Has finishing treatment had an impact on your psychological well-being?’ The interview schedule also included sub questions which it was hoped that the participant would cover in their answers, and if not then the researcher could prompt these with further questions. This is in line with the recommended number of questions for an IPA interview of between six and ten questions, with possible prompts. This usually results in an interview of between 45 and 90 minutes

for adult participants. While the interview schedule for each participant was the same, often as each interview progressed, a participant would discuss something interesting which prompted further inquiry and led to additional questions being asked. Therefore, no two interviews were exactly the same.

The second interview schedule followed approximately the same lines as the first interview as the goal of this stage of data collection was to see if there were any observable differences in patient's experiences over time. However, the second interview also gave the opportunity to probe a little deeper into some issues which had been discussed with particular participants. Therefore, the second interview schedules were tailored to each individual participant. The analysis of the first interviews often highlighted areas which were perhaps not discussed in as much detail as would have been liked. The second interview presented an opportunity to discuss these topics in more detail. This allowed for a deeper understanding of patients' experiences to be gained than would have been possible if they had only been interviewed on one occasion, while also allowing participant's experience of future disorientation to be tracked over time.

#### **4.5 Data Collection**

Data was collected using semi-structured interviews which were conducted either within the participant's home or within a room within the designated hospital in the North East of England. All participants gave informed consent to participate in the study and were reminded that they were free to withdraw from the study at any time. The semi-structured interviews lasted between 18 minutes and 2 hours, and were digitally recorded, for which the participants also gave their consent. As discussed in Section 4.3, the interview schedule consisted of a number of open ended questions about the participant's experience of cancer as well as a number of prompts around how they view the future, the functional

impact of cancer, and sources of support. The second interview followed the same pattern but also included a number of questions tailored to the participant to allow the researcher to follow up on issues which were raised in the first interview.

#### **4.6 Data Analysis**

IPA has a distinct methodology which applies to all stages of a research project. Similar to other qualitative methodologies used in psychology, the essence of an IPA study lies in its analytical focus. In IPA's case, that focus directs our analysis towards the participants' attempts to make sense of their own experiences. Typically, analysis has been described as an iterative and inductive cycle, which proceeds by drawing upon the strategies outlined below (Smith, J. A. et al., 2009).

It should be noted that the steps outlined below are a guide for conducting IPA analysis only, and depending on the research, may not be appropriate to go through them in a linear fashion. The majority of the steps outlined below were conducted by hand, while there are a range of statistical software packages available for use within qualitative research, these are not well suited to IPA, with the use of a hard copy of the transcript seen as the best way of conducting analysis (Smith, J. A. et al., 2009). The reason for this is the steps outlined below are not easily managed within a statistical software as analysis moves from the initial transcripts, to a table of themes separate from the transcripts themselves, and finally on to a table of super-ordinate themes for the data set as a whole. Therefore it is much easier to manage the data set using a word processor. A sample of the analytical process for Lucy can be seen in Appendices I to K. All of the interviews were digitally recorded and transcribed verbatim using Microsoft Word, as is recommended for IPA research the transcript was placed in a table with three columns, the left hand column contained space for the initial notes, the middle column contained the verbatim transcript, and the third

column contained space for the emergent themes. How this research project was conducted in line with the steps outlined by J. A. Smith et al (2009) is discussed below.

#### **4.6.1 Reading and Re-reading**

The first step in IPA analysis involves immersing yourself in the data (Smith, J. A. et al, 2009), which is achieved by reading the transcript several times to become familiar with its content. As is recommended, on the first reading the researcher listened along to the recording of the interview, this allowed attention to be paid to pauses, and tone of voice which are not evident in transcripts.

#### **4.6.2 Initial Noting**

The first level of analysis is the most time consuming and detailed as it entails examining semantic content and language use on a very exploratory level. According to J. A. Smith et al (2009) the key at this stage is to maintain an open mind and note anything interesting about the transcript. J. A. Smith et al (2009) describe three ways in which initial noting can be conducted: descriptive comments, focussing on describing the content of what the participant has said; linguistic comments, focussing on exploring the specific use of language by the participant; and conceptual comments, focussing on engaging at a more integrated and conceptual level. It is important when doing the first and most detailed level of analysis to combine these different notes in the one transcript, as the connections between them are critical at attempting to immerse oneself in the participants' life world. This stage of analysis was conducted in conjunction with the reading and re-reading stage. Each transcript was taken in turn with descriptive, linguistic, and conceptual comments noted on the left hand column of the transcript. Through the use of bracketing, each transcript from the first interviews were analysed in isolation with notes from previous transcripts playing no part in the analysis of subsequent ones. As with the previous stage

of analysis each of the transcripts from the first interviews was analysed before moving onto the transcripts from the second interviews.

#### **4.6.3 Developing Emergent Themes**

According to J. A. Smith et al (2009), following the first two steps means that the researcher will have a vast amount of exploratory notes at their disposal. The next step in the analysis process involves moving away from the transcripts, and using this larger data set to form emergent themes. The themes which emerge from the initial data set should be true to the original transcripts as they will contain an amount of descriptive comments as well as more interpretative comments. This is in keeping with the constructivist paradigm as this dialectical interchange between the researcher and the participants means that the emergent themes are a collaboration, as the researcher tries to make sense of the participants making sense of their experience (Smith, J. A. et al, 2009; Gubba and Lincoln, 1994).

Like the previous stages, the development of emergent themes was approached in a fairly systematic way, by going through each of the 15 transcripts in its own right and arranging the initial notes into groups. These groups contained items that both complimented and contradicted one another. For example if a participant discussed their partner as being open and communicative about cancer, whereas later on they described them avoiding talking about cancer, these could both be grouped under a theme called 'support from partner'. The name of each emergent theme was based solely on the content of the notes which contributed to it. Therefore, although the transcripts were not strictly used in the development of emergent themes, by keeping themes as closely related to the content of the notes that made them, this ensured that the participant still had a voice in theme development. Once emergent themes had been developed for all of the transcripts, a table was created for each one that included all of the emergent themes for that particular

transcript. It is important to note here that both transcripts for each participant were treated separately at this stage, so for example Rachel would have two tables of emergent themes, one for each interview. The names of themes were discussed with the supervision team and were refined on a number of occasions before agreeing on the final names presented within this thesis.

#### **4.6.4 Searching for Connections across Emergent Themes**

The next stage of analysis involves taking the chronological list of emergent themes and grouping them together to form super-ordinate themes. J. A. Smith et al (2009) describe two main methods of searching for themes. The first method involves entering the chronological list of themes on a word processor and moving items around and fitting them together. The second method involves printing out the tables and cutting each item up, putting them on the floor, or a table, and physically moving each item around so that they form piles of similar emergent themes. The latter approach was adopted for this particular research. When sorting the items into piles, J. A. Smith et al (2009) outline a number of different methods for doing so, however only those which were used in this analysis shall be discussed. The first method used was abstraction which involves identifying patterns between similar, emergent themes that can be grouped together under a new super-ordinate theme. For example, 'fear of recurrence', 'fear of the impact of cancer' and 'fear associated with an uncertain future' were grouped together as a new super-ordinate theme called 'cancer related fears'.

Another method utilised is called subsumption, which is when an emergent theme itself becomes a super-ordinate theme, as a series of related themes are subsumed into the larger super-ordinate theme. For example the themes 'adjusting to cancer', 'taking control',

information seeking', and 'religious coping', were all subsumed into the theme 'adjusting to cancer' to create the super-ordinate theme of the same name'<sup>1</sup>. Bracketing was also utilized in this stage of the analysis, while there was a lot of overlap in things that participants discussed, there were super-ordinate themes that emerged in one or two transcripts, as well as others which appeared in all of them. Once the emergent themes had been grouped into super-ordinate themes, a table was created for each participant. This table detailed each super-ordinate theme, and any of their sub-themes which emerged in that participants interview, along with a relevant extract from the transcript (See Appendix K).

#### **4.6.5 Moving to the Next Case**

Most studies will have more than one participant, therefore the next step is simply to move to the next transcript and repeat the steps outlined above. One of the key concepts of IPA analysis as discussed above is bracketing, setting aside preconceptions about the data from previous experience or previous transcripts within the dataset itself. However, there is an important skill in IPA in allowing new themes to emerge with each case, the rigour of systematically following the above steps should mean there is scope for this to happen (Smith, J. A. et al, 2009). A conscious effort was made in the research to not allow experience of previous transcripts to effect the analysis of subsequent ones. As such there are a number of sub-themes presented in the analysis chapters that emerged from only a few of the transcripts as well as ones which were more consistently discussed.

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<sup>1</sup> This theme was later renamed 'Coping with life after treatment'.



#### **4.6.6 Looking for patterns across cases**

The next stage of the analysis process involves looking for patterns across cases, and usually involves laying all of the tables out on a large surface and looking over them. While doing this, attention should be paid to the connections across cases, how themes in one case illuminate a different case, and which themes are most compelling. There are multiple ways in which the final result can be presented but more often than not it is presented in the form of a table of themes for the group, showing how themes are nested with super-ordinate themes and illustrating the theme for each participant (Smith, J. A. et al, 2009). Once this process was completed eight super-ordinate themes had emerged, with 29 sub-themes. After the initial round of analysis, and discussion with the supervision team, a number of changes were made to the names of the super-ordinate themes, the emergent themes and how they were grouped together. This process was repeated a number of times before the final grouping of themes that best reflected the experience of the participants were decided. This resulted in a final set of four super-ordinate themes entitled – cancer related fears, future disorientation, consequences of living with and beyond cancer; and coping with life after treatment. These four super-ordinate themes contained 20 sub-themes. The final master table of super-ordinate themes can be seen in Appendix L.

#### **4.6.7 Comparing data from time 1 and time 2**

IPA has rarely been utilised in longitudinal studies, (see Chapter 2 for more details), therefore there is no set way to compare the data for participants from Time 1 to Time 2. However, IPA is seen by its founders to be a creative process and therefore there is no reason why it cannot be used to analyse interview data from different time points. In fact J. A. Smith et al (2009 pp 52), discuss that using multiple interviews from the same participants is one possible application of IPA. In order to address the research objectives

it was felt the best way to conduct this stage of analysis was to repeat the steps outlined above for the second set of interviews. The ultimate goal of this process was then to create a second table of super-ordinate themes for the participants. Analysis of all fifteen transcripts was conducted at the same time, with all eight of the first interviews fully analysed before moving onto the second interviews.

#### **4.7 Reflexivity**

It is argued that all qualitative researchers should engage in reflexive practice, it is necessary for researchers to reflect on how they might impact on the research process when gathering data and during the analysis process (Shaw, 2010). Interpretative phenomenological analysis stresses the importance of acknowledging the role of the researcher in the research process, the approach to analysis should be dynamic and reflect the researchers attempt to make sense of the participant making sense of their experience (Smith, J. A., 2009). As an interpretative methodology the researcher is encouraged to acknowledge that they can impact on the research process, and that any analysis is shaped by their experience and pre-conceptions (Shaw, 2010).

In order to aid in reflective practice I maintained an informal reflexive journal. This entailed making some personal notes after each interview about how I felt the interview had progressed, what areas I felt could be improved upon for subsequent interviews, and some initial thoughts as to what interesting topics had arose in the interview. The reflexive journal represented a space where I could consider the observations that I had made, and what impact my own personal experience would have on my interpretation of the data. As discussed in the introduction chapter, having an uncle who had recently been treated for cancer I had to be aware that my own preconceptions may influence how I approached this piece of work. Using the reflexive journal as a way of acknowledging my subjectivity

aided in the bracketing process of analysis as it helped me focus and set aside my preconceptions and focus on what the participant was telling me. An added bonus of the reflexive journal was that it helped me detail any incidents when a patient was upset or appeared to be distressed. As part of my ethics application I was required to notify the clinical nurse specialists of any such incidents.

#### **4.8 Addressing issues of validity in qualitative research**

One of the key issues surrounding IPA is the question of validity, however the issue of validity is not unique to IPA, but is often raised as a criticism for qualitative research in general (Lincoln, Lynham, & Gubba, 2011). A number of guidelines for assessing the validity of qualitative research have been proposed, however the adoption of these can be counterproductive if they are used prescriptively. Barbour (2001), outlines a number of popular methods for assessing the validity of qualitative research, for example, the use of checklists which assess the quality and validity of a study (Smith, J. A. et al., 2009). The use of checklists have played an important role in conferring respectability on qualitative research, and served to remind qualitative researchers of the need for a systematic approach. However, checklists are often used as a prescriptive way of carrying out a research project, when instead they should be used to reflect on the quality of a study after it has been conducted (Barbour, 2001).

Another method researchers may use in order to make their study more rigorous is through the use of purposive sampling, this allows the researcher a degree of control over their sample, rather than being tied to the selection bias associated with pre-existing groups, such as clinical groups. A purposive sample, seeks to select a group of participants which is relevant to the research question, and cannot be generalised to the population as a whole, it is best used when the target population is quite small (Lucas, 2014). However, while a

purposive sample confers rigour to a study, many research studies will claim that they selected their sample purposively, when often the approach taken will be a hybrid between convenience sampling and purposive sampling, and do not contain the yield of participants required.

In *Interpretative Phenomenological Analysis: Theory, Method and Research* J. A. Smith et al (2009) outline a number of methods which can be used to assess the quality and validity of qualitative research. For the purpose of this present study, the criteria outlined by Yardley (2000) and Yin (1989) were adhered to as a way of ensuring validity and quality. In her paper, Yardley sets out four principles for assessing the quality of qualitative work, these are: sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance:

Sensitivity to context can relate to a number of facets which are equally important such as context to theory and an awareness of previous research in the area. This is achieved by conducting a thorough literature review and identifying where the proposed research fits alongside current theory. It is also important in qualitative research to have a good grounding in the philosophical approach which has been applied to the topic, something which has been discussed extensively in this thesis (Yardley, 2000). The most important area to display sensitivity to context is with the data itself, a good IPA study will always have a considerable number of verbatim extracts from the participants to compliment any arguments made, and this gives the participants a voice in the study whilst allowing the reader to see how the interpretations have been made (Smith, J. A. et al, 2009). Therefore, in the results chapters to follow, extensive use has been made of verbatim extracts from the participants which justify why certain sub-themes have been grouped together. Also, sensitivity to context was used in conjunction with the hermeneutic cycle, as the interpretation from one theme is linked not only to the extract which accompanies it, but

also to extracts from other sub-themes as well, so as to show how the interpretations link together.

A researcher's commitment can be displayed by making sure that a participant is comfortable throughout the interview process. Furthermore, the sheer act of carrying out all of the interviews necessary to answer the research question, and immersing yourself in the data demonstrates the researcher's commitment (Yardley, 2000). A rigorous study is one which is thorough, where an appropriate sample has been recruited, who are homogenous in nature and relevant to the research questions. This was achieved by recruiting male and female patients living with and beyond various cancers. The analysis should also be conducted to a satisfactory level, and following the steps outlined above should ensure that a rigorous study is conducted (Smith, J. A. et al, 2009). Commitment to the present research was demonstrated by conducting two interviews with each participant, and tracking their experience of future disorientation over time. Also, rigour has been displayed by completing a number of rounds of analysis to refine the themes in order to best demonstrate the experience of participants.

Transparency relates to how clearly the stages of analysis have been written up (Yardley, 2000). As can be seen in the sections above, a clear and detailed guide to the analysis of this study has been provided which should ensure transparency. Furthermore, in the results chapter there are a number of extracts from transcripts to support the themes, with signposting back to previous examples given, which support the connections made between themes, aiding transparency. Coherency relates to the arguments presented in the results section, the themes should be tied together logically, and someone not involved in the research process should be able to follow a clear and coherent argument throughout. Finally, impact and importance suggests that the validity of a piece of qualitative research

can be judged on whether it tells the reader something interesting and important (Yardley, 2000).

The second set of criteria for ensuring the quality and validity of the present research was to follow the independent audit described by Yin (1989). The principle of the independent audit according to Yin (1989) is that a researcher should file all of their data in such a way that another researcher could follow the paper trail from initial documentation to the final report. This ensures clarity in how you have come to your interpretations and come to the arguments you have made about the data. Within this particular project, the supervision team have been a source of support in providing a fresh pair of eyes for looking over the paper trail. They have also provided helpful suggestions for the possible refinement of, and the positioning of themes within super-ordinate themes, and thus ensuring that the interpretations and arguments made are logical, and make sense to the reader. There is a danger that the desire for validity and reducing qualitative research to a list of technical procedures is overly prescriptive. This can result in the illusion of higher quality research if the researcher has focussed too much on validity, and not on making the most of their data (Barbour, 2001). Even if a researcher were to follow the steps outlined by Barbour (2001), Yardley (2000), and Yin (1989), this does not guarantee the quality of the research. The following three chapters will outline the results of the four super-ordinate themes which emerged from the data.

## **Chapter 5 – Cancer Related fears and Consequences of living with and beyond cancer**

The following three chapters outline the results of the data analysis steps detailed above. The literature review presented in Chapter 2 was used to develop the interview schedule used as the method for collecting data. The purpose of the interviews was to explore the real life experience of future disorientation in the study participants, with the resulting data analysis being used along with the literature review to develop a conceptual framework which is presented in Chapter 8.4. After following the analysis steps outlined in Chapter 4.7, twenty sub-themes emerged from the interviews, which were grouped into four super-ordinate themes: cancer related fears, future disorientation, consequences of cancer treatment, and coping with life after treatment (see table 5.1 below). Sub-themes were grouped into super-ordinate themes using the processes of abstraction and subsumption as described in Chapter 4.7.

The results of both interviews are presented in the same chapter as this allows for a comparison of participant's experiences over time. The present chapter outlines two super-ordinate themes, cancer-related fears and consequences of living with and beyond cancer. It was decided to present these super-ordinate themes in the same chapter as both relate to the first research objective which sought to explore the relationship between fear of recurrence and future disorientation, and the relationship between other consequences of cancer and future disorientation. These results were then used to inform the conceptual framework (presented at the top of the framework in Chapter 8.4) around potential causes of future disorientation. ....

**Table 5.1 – List of super-ordinate themes and sub-themes**

Super-ordinate Theme	<i>Sub-Themes</i>	
Cancer Related Fears	<i>Fear of Recurrence</i> <i>Fear associated with an uncertain future</i>	<i>Fear of the Impact of cancer</i>
Consequences of living with and beyond cancer	<i>Infertility as a consequence of cancer treatment</i> <i>Loss of Control</i> <i>Recurrent thoughts related to cancer</i> <i>Physical Consequences of cancer</i>	<i>Anxiety</i> <i>Impact in family life</i> <i>Occupational Concerns</i>
Coping with life after Treatment	<i>Making sense of symptoms</i> <i>Psychological and physical adjustments</i> <i>Hope</i> <i>Social Support</i>	<i>Lifestyle Adjustments</i> <i>Religion/Spirituality</i> <i>Formal Support</i>
Future Disorientation	<i>Future Plans</i> <i>Life on Hold</i>	<i>Feelings of not recovering from cancer</i>



## **5.1 Cancer-Related Fears**

As noted in Chapter 2, cancer related fears are common amongst people living with and beyond cancer (Ghazzali et al, 2012; Llewellyn et al, 2008; Taylor et al, 2010; Taylor et al, 2011). Therefore, it is not entirely surprising that similar fears have been found in this sample. Participants were not asked directly about their cancer fears as the researcher was aware that this could be a sensitive issue and did not want to induce this fear in participants who had not previously considered recurrence as an issue. It was hoped that the interview questions ‘How did you feel when you came to the end of your treatment?’ and ‘What does the future hold for you?’ would facilitate discussion around cancer related fears. Furthermore, given that the scope of the second interviews was to see how participants’ experiences have changed over a period of 6 months, then it would be expected that discussion about their cancer related fears would again be a central theme.

This theme served to illustrate that experiences of fear related to a cancer diagnosis are quite a common experience amongst participants, and that it can come in a number of different forms. Three sub-themes emerged from the data which were grouped together to form this super-ordinate theme: fear of recurrence, fear associated with an uncertain future, and fear of the impact of cancer. Fear of recurrence explores a patients concern that cancer will come back; fear associated with an uncertain future explores patients concerns that they may die prematurely because of cancer; and fear of the impact of cancer looks at patient’s concerns about what impact a cancer diagnosis will have on their lives.

It should become apparent from the following quotes that cancer related fears are diverse, and the impact of them may be long term or short term. For example while some elements of cancer related fears may be experienced long term, other fears such as fear of

recurrence, appear to change over time with certain events that can either trigger these fears or escalate them when already present.

### 5.1.1 Fear of recurrence

The concept of fear was something that repeatedly arose within the interviews. Many of the participants expressed concern that their cancer could come back at some point in the future; this was often prompted by factors such as: aches and pains, similar symptoms to those experienced at the time of diagnosis, or if they were approaching a follow up appointment. Fear of recurrence was a common concern expressed by participants, with Rachel, and Rob expressing these fears at both interviews. Lucy on the other hand expressed fear of recurrence in the first interview, and by the time of the second interview had developed another tumour. In her case there was a transition from fear of recurrence to fear of progression. For the remaining participants, Geoff, Sarah and Lindsay their experience of fear of recurrence seemed to change over time, only John failed to discuss fear of recurrence at either interview.

*Rachel Int 1- "About a year ago, which is where the anxiety came from I think as well, I found a lump in me breast and it was like, went to the, the, put off a bit... in the end like I had to go[to the doctor] ... went and then they were great, got me straight in cause they, they, well you think you're going to go to the doctors and they'll say it's nothing to worry about, the doctor says well there is something to worry about."*

*Rachel Int 2 - "Really I should, cause you, you, in me mind and it was there, thinking well what, what's causing it, and you think, well you're worrying about it and your anxious about it and that's probably why you're, you know (Grant – yeah) you're getting constipated but I should go getting it checked out really .... (Grant – why do you think you don't go?) Probably (speaking quiet and slow) don't want them to find anything"*

The quotes above from Rachel highlight that fear of recurrence may be a stable construct after cancer treatment, expressing them in both interviews. This is highlighted by the fact that in both extracts she mentioned the experience of sensations or symptoms in her body

which she thought may be a sign of recurrence. In the first interview she discussed finding a lump on her breast, and in the second interview she was concerned that constipation was symptomatic of cancer recurrence. Both of these incidents were accompanied by a subsequent reluctance to go to her doctor, for fear that they might confirm that she had suffered a recurrence of cancer. Her reasoning behind this was explained when she stated in the second interview that she did not report these sensations as she did not want the doctors to find anything wrong. This would suggest that she would rather live with these fears of recurrence, than risk having them confirmed by her doctor. What is interesting from these quotes is that her avoidance in reporting sensations to her GP has persisted over time. Despite discussing in the first interview that when she eventually went to the doctor to have the lump in her breast examined she was told it was not a sign of cancer recurrence, she is still reluctant to have sensations checked 6 months later. This would suggest that not only is Rachel's fear of recurrence persistent over time, but also that her method of coping with fear of recurrence, avoidance, is also persistent over time. Coping strategies are discussed in more detail in Chapter 7.

*Rob Int 1 - "I didn't want to put meself in a position of having 4 cycles (chemo) and then have it come back and I thought if I have 8, it might not, so I'll have the 8 and I didn't do the trial, I was just basically giving meself the best chance I could"*

*Rob Int 2 - "(G – Do you think that is coming into your thinking with the exercise and the weight losing as well, you said you think you have got less chance of cancer coming back if you, if you are fitter?) Yeah less weight, fitter, healthier, stronger, yeah (Grant –mhmm). I did, go to (life science centre), I don't know if I told you about that (Grant – I don't think you did, no) right well my cousin's, cousin is a specialist bowel cancer nurse (Grant – you told me about her, yeah, yeah) yeah she suggested that if I went to the (life science centre), they might be interested to look at the (Grant – mhmm) piece of the tumour (Grant – mhmm) to see if it was caused by genetics or not (Grant – okay) and that so we did that and they said not, I'd just been unlucky"*

While Rob did not explicitly express his fear of recurrence in both interviews, there is evidence in the above quotes to suggest that his fears continued across the two interviews.

In the first interview, Rob discussed when he was offered the chance to take part in a clinical trial which would have involved receiving half of the normal dose of chemotherapy, with four cycles instead of eight. The above quote highlights that Rob was willing to undergo four extra cycles of chemotherapy that may not have been necessary, as he would have blamed himself if the cancer came back. This suggests that he has an underlying fear that the cancer could come back, which is further highlighted when he said “have it come back” suggesting that thoughts about recurrence had crossed his mind. In the second interview, there is evidence that Rob was still experiencing fear of recurrence, although again it is not explicitly articulated. Rob seemed to be associating cancer with physical fitness, and felt less at risk of cancer recurrence now that he was feeling fitter. In the last interview, Rob mentioned that he felt that he was not as fit as he could have been when he was diagnosed, and it seems that he felt partially responsible for developing cancer. This is reinforced when the specialist at the life science centre told him that his cancer was not genetic, and may be why he felt that regaining fitness would minimise his risk.

While many participants will exhibit fear of recurrence, for some those fears will be realised, in the following quotes, Lucy’s fears of recurrence have transitioned to a fear of cancer progressing:

*Lucy Int 1 - “You know so it’s probably the lungs that will get us in the end. Mhmm, it’s how I feel anyway, I don’t think I’m finished with cancer to be honest with you”*

*Lucy Int 2 - “I’d started getting these pains and things again, well the pains have never really gone away, me abdomen and stuff like that... decided to send us for another scan (Grant – okay), and here, it was showing some lesions and shadows and stuff, er, me lower kidney, me right kidney area, stomach, in between the stomach and the pancreas was a little sort of tumour. .. They could put me on a tablet called Tamoxifen which, has been sort of shown in 30% of the cases to reduce, or hold whatever’s going on... The thought of chemo, is just something I really do not wish to have to do again”*

In her first interview Lucy had a strong belief that she would suffer a recurrence of cancer, which was highlighted by her use of the phrase “I don’t think I’m finished with cancer”. The fact that Lucy has had cancer on two previous occasions may be contributing to these fears. Furthermore, she seemed to have a strong sense that if her cancer does return then it would be lung cancer. The fact that Lucy continued smoking since being diagnosed with cancer could be the reason why she felt she would suffer from lung cancer, and may also be adding to her fears of recurrence. The quote from Lucy in the second interview highlighted the transition of Lucy’s fears from fear of recurrence to fear of cancer progression since the discovery of a new tumour. Lucy was concerned about the prospect of the tumour progressing and medication not slowing the growth of the tumour. This is evidenced when she stated her fear regarding having to undergo another course of chemotherapy. This would suggest that her previous experience of cancer treatment was shaping these fears.

However, experience of fear of recurrence was not stable for all of the participants in this study. The following quotes suggest that certain triggers can cause fear of recurrence to emerge at any point along the cancer journey:

*Geoff Int 1 –“ I don’t sort of really think (because) I’ve had (it) that it can come back at any time so I best not make long term plans. So working on that basis, I don’t let it affect us, really”*

*Geoff Int 2- “I had some symptoms, it lasted about three months which did cause concern and obviously when erm whe... when you’ve had something like I’ve had, whe... when there’s something not right you immediately think ‘oh it’s back’ and it, it, it’s difficult not to think that way... I actually got in touch with CNS and I ... says erm look you know I’m getting nagged off the wife sort of thing to get in touch with you, got these symptoms, what you thinking?”*

The above quotes highlight the change in experience of fear of recurrence for Geoff. In the first interview he seemed unconcerned about the possibility of his cancer returning, this is emphasized when he expressed that he does not think just because he has had cancer that

it can come back. Furthermore when he said “I don’t think - I’ve had it, I best not make long term plans” this would suggest that he felt able to get on with his life and did not let the fact that he has had cancer affect him in this regard. However, by the time of his second interview the occurrence of potential cancer symptoms have led to fear of recurrence developing for Geoff. This is evidenced by the phrase ‘you immediately think oh its back’ with Geoff expressing that it was difficult not to imagine that it had returned. What is interesting is that despite Geoff’s fear of recurrence he did not report his symptoms straight away to his CNS, and only did so because his wife asked him to do it. His avoidance of reporting symptoms to his CNS may be his way of coping with his fear of recurrence, as if he does not report his concerns then he cannot be told he has recurrent cancer. The use of avoidance coping techniques is something which was discussed in the literature review (Chapter 2.6) as being maladaptive, and could reinforce fears of recurrence.

Like Geoff, Sarah did not consistently express explicit fears of recurrence, with Sarah this was only discussed in the second interview:

*Sarah Int 2 - “I’m not nervous about the having it done (colonoscopy), and I’ll probably have to go on me own for the results... if they take a biopsy then they will have to take it away, just better not, better not find anything. I just keep thinking, well I had no symptoms the first time, so you know, wait and see”*

The above quote from Sarah suggests that fear of recurrence can be triggered by certain events, as Sarah did not discuss fear of recurrence, or a lack of, in the first interview. In Geoff’s case the experience of symptoms triggered his fear of recurrence. However for Sarah, the activation of fear stems from her approaching hospital follow up appointments. If her thoughts about recurrence are linked to approaching clinical appointments, then perhaps she did not have an imminent appointment at her first interview. If this was the case then it would suggest that experience of fear of recurrence may fluctuate over time,

with certain events activating or re-enforcing these fears. Another salient perspective, given that Sarah was diagnosed at a screening with no prior symptoms, is that her prior experience reinforces her vulnerability and belief that any future hospital appointment is another risk that clinical staff may diagnose cancer again.

While Paul discussed fear of recurrence in the first interview, he declined to take part in the second interview, making a comparison over time not possible in his case.

*Paul Int 1 - "Well I'm gona be okay, as long as I keep meself right and I've done it ever since, I've been right. If I just keep meself fit, I mean I put a bit of weight on now since I finished in eh September but eh I'm going to start up me walking again and me swimming like I used to"*

While Paul does not explicitly express fear of recurrence in his interview, the language he used suggests there is still an element of those fears present. This is evidenced by Paul talking about "being okay as long as I keep meslef right", like the quote from Rob outlined previously. This would suggest that Paul felt his cancer was linked to physical fitness and suggests that he felt more at risk of cancer recurring if he does not keep himself fit.

Over the course of the two interviews the majority of participants have expressed some level of fears of recurrence. The above extracts support the idea that the experience of fear of recurrence can persist over time (as discussed in the literature review, Chapter 2) in that most people who expressed their fears in the first interview also had those fears at the second interview. However, the level to which they explicitly express these concerns does seem to be affected by certain triggers such as experience of symptoms, or upcoming follow-up hospital appointments. The uncertainty caused by these triggers can escalate fears of recurrence, which is then only alleviated if the symptoms go away, or when the results of the follow up check show that the cancer has not returned. However, one of the consequences of fear of recurrence appears to be a reluctance to report any symptoms which are experienced, for fear that their suspicions of cancer returning will be confirmed.

This is obviously counter-productive as if the cancer has not returned then they are worrying for no reason, and if it has returned then the earlier it is caught the better. The use of negative coping strategies, such as avoidance, discussed in more detail in Chapter 7, have been identified as leading to adverse outcomes of cancer such as depression and anxiety (Llewellyn, Weinman, McGurk, and Humphris, 2008). If the cancer does recur, then the fears associated with recurrence can then be displaced by fears that the cancer may have progressed to the stage that aggressive treatment is required, and memories of previous treatment can contribute to these fears. Different patients seem to adopt different coping strategies to deal with fears of recurrence, Geoff and Rachel appear to adopt a negative coping strategy of avoidance by not reporting their concerns, whereas Rob seems to adopt a positive approach accepting that there is a risk that his cancer could come back and opting not to try an experimental lower dose of chemotherapy. This may have implications for future disorientation as Roberts and Clarke, C. L., (2009) demonstrated that a failure to adapt to a new future following cancer diagnosis can lead to future disorientation. Therefore, the use of positive coping strategies in the face of fear of recurrence may help to prevent or lessen the impact of future disorientation.

Studies have shown that the prevalence of fear of recurrence in colorectal cancer patients can vary from 5-69% (Frykholm et al, 1995), and between 20% and 50% of women with gynaecological cancer (Myers et al, 2013). Therefore it is not surprising that a number of participants in this study have expressed fears of recurrence, with both gynaecological cancer patients, Lucy and Rachel discussing these fears at both interviews. Similarly, of the patients with colorectal cancer: Lindsay, Paul, Rob, Sarah, and Geoff all expressed fear of recurrence in at least one of the interviews, with Lindsay discussing them in both. Studies have shown that fear of recurrence tends to be stable over time in patients with head and neck cancer (Ghazzali et al, 2012) however, the results from this study would



suggest that the experience of fear may change over time. This could suggest that those patients whose fears persisted over time were suffering from higher levels of fear of recurrence, or distress associated with these fears, than those who only expressed these fears at one interview. Furthermore, referring back to the literature review in Chapter 2, fear of recurrence can have negative consequences such as anxiety, poorer quality of life, and patients can feel less informed about their illness (Handsichel et al, 2012; Hong et al, 2010).

### **5.1.2 Fear associated with an uncertain future**

Like fear of recurrence, fear associated with an uncertain future was not something which was directly asked of the participants in the interviews however, the expression of these fears were common. The reasons behind these fears seemed to vary between participants and they do not appear to fluctuate across the two interviews. Participants who expressed fears related to an uncertain future in the first interview continued to express these fears 6 months later and vice versa. The continuation of fear associated with an uncertain future over the two interviews is exemplified by the following quotes:

*Geoff Int 1 - "I woke up on the Wednesday morning and the pain was incredible and the wound burst and there was a lot of gunge coming out and down me leg and everything and a... a... I lay on the bed and the immediate thought I had was I was gonna die because I'm thinking if there's that much pressure going onto the wound what's it like on the bowel which has just been cut open and stapled back together."*

*Geoff Int 2 - "Yeah eh I mean I think you get to an age where you know, you think well, I'm the wrong side of 50 now I'm er, I just probably an average person at this age, I don't think I'll not do that in case the cancer comes back but I mean I', getting to an age where it's on your mind you know that anything can take you, heart attack, anything."*

In the first interview Geoff's fears of dying seem to have been triggered by a traumatic event, waking up with his wound burst and being in intense pain led him to believe that he was dying. Furthermore, Geoff says that he lay on his bed when these thoughts occurred to

him and this emphasizes how strong his fear was, as it suggests that he was so convinced that he was going to die that there was nothing he could do about it. In the second interview, while he does not explicitly express his fears, he does mention more general fears related to an uncertain future in relation to his age. It is perhaps surprising that Geoff's thoughts of dying have become more general given the recent incident where he thought he was experiencing symptoms of cancer recurrence, as discussed in Chapter 5.1.1. However, when considering that he had been for a scan and told his symptoms were not indicative of recurrence, this then may explain why his fears are not necessarily focussed on his cancer as he was still unaware what caused these symptoms. Had his second interview come before the scan, perhaps the focus of his concerns may have been different. This suggests that fear associated with an uncertain future can persist over time, although the cause of the fears may change over time depending on certain factors such as the experience of symptoms.

*Lucy Int 1 - "I've pushed meself and I got back to a normal life but the dark clouds started coming in, em (pause). This you know am I going to make it, every night going to bed and thinking, is this you know is this the last night am I not going to wake up in the morning"*

*Lucy Int 2 - "I must admit I am on a right downer at the minute, erm can't see any light at the end of the tunnel, just keep thinking you know, am I going to be here at Christmas, is this it this time, you know"*

Lucy's fears appear to become more salient at night as she describes the feelings as occurring every time she goes to bed. This may suggest that having nothing else to occupy her mind may cause her to focus on these fears. Lucy also talks about "dark clouds" which could describe thoughts about dying or other unpleasant thoughts associated with her cancer. What is interesting to note from this example is the avoidance of the word death, referring to dying as 'not making it' suggests that Lucy uses avoidance as a way of coping with unpleasant thoughts. It is almost as if by saying the word death, or addressing her fears, may make them seem more real. As discussed in the previous sub-theme the use of

negative coping strategies such as avoidance may lead to outcomes such as anxiety and depression. In the second interview, Lucy's fears have been compounded by the discovery of a new tumour which may have reinforced her fears. Like Geoff, uncertainty seems to be a key factor related to a fear associated with an uncertain future for Lucy, as in the first interview she talks about her uncertainty of going to bed each night and not knowing if she was going to wake up in the morning. This feeling of uncertainty is echoed in the second interview, as in the quote above, Lucy talks about her uncertainty as to whether or not she will be around at Christmas. This would suggest that the discovery of a new tumour have reinforced Lucy's fears associated with an uncertain future.

Like the above quotes, for those participants who did not explicitly discuss dying or fear associated with an uncertain future, there was a continued lack of discussion around this area in the second interviews, as exemplified by the following quotes:

*Paul Int 1 - "When I found out I says oh got to get on with life, if I'm going to die I'm going to die; that's the way I look at it now. I mean I've done well cannae grumble at my age, there's not many get to 65"*

*John Int 2 - "Just chuffed to bits, like that I've, I've made a full recovery so far an everything so they're just brilliant about it so, like I say, like I said the last time, they've got a, I've got a disabled sister that's 100% needs care, 24 hour 7 days a week so I mean like got, them to care for so they know that if she can like get on leading life like she does, they know I can recover from this as well so..."*

In the above quote, Paul discusses his feelings that he has led a good life and when he says 'if I'm going to die I'm going to die' this indifference suggests that he is not afraid to die and that when the time comes he will accept it. This echoes the views expressed by Rob in the previous sub-theme which suggests that Paul is using positive coping strategies which may help prevent or limit the impact of future disorientation. This is discussed in more detail later in this chapter. Furthermore, while Paul is not afraid of dying, this quote does highlight that cancer can leave people living with an uncertain future as he states 'if' he is

going to die, suggesting that, like the other examples above, he is living with an uncertain future. As discussed, John made no mention of death and dying in the first interview but his thoughts on his recovery from cancer in the above quote would suggest that he has no immediate concerns regarding his life expectancy. Given that John was one of the youngest participants in the study this may be an explanation for why he does not seem to express the same levels of fear associated with an uncertain future expectancy as some of the other participants. However, there is a degree of ambiguity in the above extract from John, as although the term ‘full recovery’ suggests that John feels confident that he is no longer at risk of dying from cancer, he later states that his parents ‘know I can recover’ suggesting that he is not yet sure that he is going to be ok. Had he said they know I have recovered then this would be more indicative of John’s certainty that his is going to be ok in the long term. John’s recent experience of sensations which he felt were indicative of cancer recurrence may have cast some doubt over John’s feelings about his recovery and may explain the ambiguity in the above quote.

However, while for the above participants fear, or lack of, associated with an uncertain future seemed to be consistent, there was a change in the expression of these fears for the following participant:

*Rob – Int 1 - “I’m fine, feel confident I’m alright but every couple of months on the television some celebrity dies of bowel cancer it’s always coming back at you, Sid Waddell, Robin Gibb... It just reminds me of what it could of been, and still could”*

*Rob Int 2 - “I’ve got a lot stronger and fitter, so I can walk like up hills without getting out of breath and er I started going swimming, 104 lengths in 90 minutes... I started off just doing 20 lengths and me legs felt a bit wobbly but an hour and a half now and 104 lengths and I feel fine and I go to the gym twice a week... feel fitter, stronger, healthier, better, just feel like I’m making, going in the right direction”*

In the first interview, Rob discussed that thoughts about dying from cancer became salient when he heard of others, such as celebrities, dying from cancer. His fear associated with

an uncertain future is implied when he stated that when he heard about these people dying from the same cancer he was diagnosed with, it reminded him of how it could have been, and still could. This would suggest that there was some part of him that believed he was not completely safe, however he stated that for the most part that he felt confident that he was going to be okay, and that he only had these thought every few months. However, in the second interview Rob did not discuss thoughts about dying at all which may suggest that he was no longer holding onto these fears and felt that he was recovering well. This is exemplified when he said that he felt that he was moving in the right direction. Furthermore, in the second interview Rob seemed to associate his recovery with physical fitness which was discussed in the previous sub-theme. He discussed how he was now physically fitter and related this to his belief that he was moving in the right direction. This would suggest that like fear of recurrence, fear associated with an uncertain future may be influenced by factors such as the experience of symptoms or a feeling that one is not recovering in the manner they would expect. Since Rob felt that his fitness was progressing, this may have helped to eradicate these fears and led him to believe that he was now recovering well.

Fear associated with an uncertain future seems to stem from concerns that a patient may die as a result of their cancer, despite the fact that they have finished treatment. What is interesting to note within this sub-theme is the avoidance of the word death, while many participants appear to have had concerns that they are going to die at some point after treatment, the vast majority of them avoided using the word death. Instead, patients would say things like “I won’t be here at Christmas”; “Will I wake up in the morning?”; “I’m not ready to go” and “Anything can take us”. While none of these phrases in themselves use the word death, they do imply that the patient has concerns about their future life expectancy. This can then be interpreted as a fear that they are going to die as a result of

their cancer. Fear about dying after one has finished treatment for cancer does not appear to have much attention in the literature, and it may be because people do not use the word death. One paper has reported concerns about dying amongst women living with and beyond breast cancer found that it may lead to patients avoiding talking about cancer with their family, for fear that this may lead to a discussion around death (Walsh, Manuel, and Avis, 2005). The results presented in this section highlight that fear of an uncertain future, or fear of dying, may be an ongoing issue for people who are living with and beyond cancer which is not being addressed due to a reluctance to discuss these fears. Furthermore, in terms of the present study, a fear that you may not be alive for much longer could have an impact on a patient's ability to plan for their future, as patients may be reluctant to make plans which they may not be around to fulfil.

Unlike the fear of recurrence sub theme discussed in Section 5.1.1, fears associated with an uncertain future appear to be more consistent over time. Fear of recurrence seemed to fluctuate over time for the patients in this study, and seemed to be influenced by a number of factors such as perceived symptoms or upcoming hospital appointments. However, fears associated with a future life expectancy appeared to be more stable, with only Rob experiencing a change in his experience of them. Interestingly there does not appear to be a straightforward connection between fear of recurrence and fear of an uncertain future, as while Lucy, Lindsay, John, and Paul either experienced, or did not experience, these fears consistently across the two interviews, there was no consistency in the expression of these fears for Geoff, Rob, Sarah and Rachel. Lucy was the only participant who expressed both of these fears in each of the two interviews, and therefore may be related to the fact that she has developed a new tumour. Lindsay on the other hand did not explicitly express fear of recurrence or fears associated with an uncertain future at either interview. However, for the other participants there was no connection between these two sets of fears; for example

Rob discussed fear of recurrence in both interviews but fear associated with an uncertain future at only the first interview. Geoff on the other hand expressed fears relating to an uncertain future at both interviews but only expressed fear of recurrence during his second interview. This would suggest that just because a patient has a fear that their cancer may come back, this does not necessarily translate into a fear that they may die as a result of cancer recurrence. Likewise, if a patient does have fears that they are living with an uncertain future, this does not necessarily mean that they are concerned about cancer recurrence.

### **5.1.3 Fear of Impact of Treatment**

A fear that was expressed by a number of participants in their interviews was the fear of the consequences of their cancer treatment, such as having a stoma fitted after surgery, or having to take medication. While fear around the fitting of a stoma is not an issue that affects all patients diagnosed with cancer, it seemed to be a significant concern for some of the patients in this study. Unlike fear associated with an uncertain future, and fear of recurrence this is not something which remains a significant threat for the majority of participants unless they were to suffer a recurrence of cancer, yet this fear was consistently expressed across the two interviews. While in the first interviews participants merely expressed their fear of this outcome, the second interview saw them go into more detail about why they held these fears. Two significant factors seemed to be responsible for this fear, worries about body image and a realization that a stoma will represent a significant lifestyle change whether it is temporary or permanent. This fear is highlighted in the quotes below:

*Lucy Int 1 - "Nurse came up and I says 'what?' She says we have to mark you just in case (for a colostomy bag). Well honest to God pah me feet again I just had this horrible dread feeling. Oh no not that on top of everything else"*

*Lucy Int 2 - "Having to have a colostomy would be just another nail in the coffin to me. As regards femininity, and sort of feeling sexual I suppose (Grant – yeah), yeah, I mean that's out the window now at the minute, and I don't think (partner) understands that either, bless him, oh dear."*

Lucy expressed her concern about the prospect of having to have a stoma in the quote above. She discussed a feeling of dread when the nurse marked her abdomen for a stoma prior to surgery. Looking at the quote from her second interview, reasons why patients are averse to the idea of having a stoma begin to emerge, as Lucy seemed concerned that the stoma would have had a negative impact on her body image and sexual function. This is emphasised when she stated that the stoma would be another nail in the coffin with regards her femininity, this suggests that she already had concerns about her femininity and that this would have been another setback in this regard. Furthermore, she also mentioned that she would feel less sexual if she had to have a stoma. However, she also mentioned that 'that is out of the window at the minute anyway' suggesting that she was not sexually active with her partner at the time of the interview, even without having a stoma. Given that Lucy mentions elsewhere in her interview that she felt as if she had aged ten years in the last year, it is possible that she already had a negative body image. The above quote suggests that she felt that a stoma would further negatively impact on her sense of self, which may explain why she was fearful of that being an outcome of her surgery. A feeling of relief about not having a stoma after surgery was echoed by Paul "That was the worst thing I was worried about in case I had to wear the colostomy bag on - *Int 1*"; and Rob "didn't have the bag so that was fantastic – *Int 1*" This highlights that concerns about having a stoma as a consequence of surgery for cancer is quite a common concern for patients of both colorectal and gynaecological cancers.

However it is interesting to note that the only participant in the sample who had a stoma following surgery for his cancer, did not view it in a negative light and seemed to have adapted well to the change. However, despite coping generally well with having a stoma,



the quote from John's second interview below, highlights that he still had some concerns around working in the catering industry with a stoma:

*John Int 1 - "Just took it in my stride (stoma), everybody, I think everybody has been quite surprised how, like how well I have taken it in my stride, and I tend to do it for other people as well like my wife and my family"*

*John Int 2 - "Just basically wearing a bag like on me stoma (Grant – mmmm) basically I would have no control over me bowels (Grant – yeah) so obviously if I'm serving food to customers, if I know that I'm going to the toilet basically, (Grant – yeah) when I'm serving people food, I just don't think I'd, well here I'm having a poo but there you go there's your food sort of thing (laughs), basically that's the way I would of feel, would of felt about it, I would of like struggled with that I think, but, but like I say that's one of the reasons why I wanted to try the irrigation and it's been ideal so..."*

The above quote suggests that John was coping well with the lifestyle adjustment of having a stoma following his surgery. John stated that he 'took it in his stride, which suggests that he felt the stoma had a minimal impact on his day to day life. However, when considering quote from the second interview it becomes apparent that John had to make a significant change to his lifestyle as a result of his stoma in relation to his occupation. At the time of the first interview John had not returned to work yet, and had not decided whether or not he would feel comfortable wearing a bag over his stoma while at work as a catering manager. The phrase 'I would have struggled with it' emphasises that John would have felt uncomfortable knowing that he could be serving food to customers while the bag could be potentially filling up. On the other hand, as he had only recently finished his primary treatment for cancer it may just be that he had not gotten used to the idea of having a permanent stoma yet and the idea of a colostomy bag was not yet an everyday event for him. Perhaps as he became more accustomed to living with his stoma in the future he would be more comfortable wearing the bag while he is at work.

While many participants expressed their concern about having a stoma as a result of their surgery, for other participants there was a fear associated with a need to take medication after their surgery. This is exemplified in the following quote:

*Rachel Int 1 - "Trying to lose the weight you know... as soon as I stopped taking the HRT I seemed to lose weight and then been told that I then had to take it again it's made us, it's made us a bit like, I was totally neurotic (G – yeah) a few weeks ago, just about it, thinking like, you know I'm going to pile all the weight on"*

*Rachel Int 2 – "I just got absolutely petrified of, of taking it and got to the point where, I just like, really hysterical crying... they'd put us on like bigger dosage of this premarin and I just wanted to go back on the first lot that I was in hospital with, was never bad off it and that so just asked the doctor if I could take that and I've been great ever since"*

In the first interview Rachel appeared to associate hormone replacement therapy (HRT) with her fluctuating weight following her surgery. She felt that as soon as she stopped taking it then her weight went down, and therefore felt that by resuming HRT she would 'pile all the weight on'. Her aversion to HRT was emphasised when she discussed being neurotic, suggesting that she felt so strongly about not taking HRT that even the mention of going back on the drug was enough to cause a strong emotional reaction. In the second interview however Rachel had addressed her fears around HRT by discussing them with her consultant. Rachel had previously been prescribed another HRT drug, which she had taken without the side effect of weight gain. Upon mentioning this to her clinician, they took the decision to change her treatment and she subsequently had no problems with her weight. This is interesting in Rachel's case as in the fear of recurrence sub-theme it emerged that she took the opposite approach to these fears, avoiding reporting symptoms. This suggests that her experience as a patient allowed her to comfortably identify the course of treatment that is right for her, thus emphasising that adopting a positive coping strategy may alleviate fears related to cancer.

The results presented here serve to show that, while only one patient in this study actually had a stoma after their surgery, a large number of participants harboured concerns about this being a possible outcome. One of the consequences of having a stoma is that it may affect how participants are able to plan for their future. The example of John, who has a permanent stoma, highlights that it can impact on a patient's life and how they plan for their future. He had considered changing career as he did not want to wear a colostomy bag while working, and would not feel comfortable with spur of the moment plans as he needed to have time to irrigate his stoma. The fact that patients who have not had a stoma also share some of the concerns expressed by John, indicate that they too would have issues around making future plans after having a stoma.

Fears related to the impact of cancer treatment can also be attributed to the prescription of medication after treatment, as was the case with Rachel. She was concerned about returning to HRT treatment as she felt that this had led to her gaining weight the last time she had to take it and led to feelings of anxiety. However, as time progressed Rachel addressed her fears by discussing them with clinical staff, thus taking ownership of her treatment. This resulted in her being prescribed a different HRT medication, and has seen a subsequent reduction in her anxiety.

While there have been numerous studies which have looked at the impact of having a stoma following treatment for cancer, which would be relevant to the experience of John (Bekkers, Knippenberg, Dulmen, Borne, & Berge Henegouwne, 1997; Sharpe, Patel & Clarke, S., 2011; Zajac et al, 2008;) there does not appear to be any literature around patients perceptions, or fears of, a stoma prior to their treatment. As Lucy discussed, the first she knew a stoma could be a potential outcome of her treatment was just before her surgery. However, as patients are briefed about the possibility of a stoma before they are

treated it is possible that Lucy either did not fully comprehend this, or perhaps did not feel it was a real concern for her until it was brought up pre-op.

The above sub-themes all have the potential to lead to feelings of future disorientation, which is discussed in more detail in the following sub-themes. While fear of recurrence was identified in the literature as being a potential source of future disorientation this was not the case for fear of an uncertain future or fear of outcomes of cancer, which had not been anticipated. The results presented in the sections above, point to the fact that other cancer related fears have the potential to lead to future disorientation and can have consequences for patients if they fail to come to terms with them. Fear of an uncertain future for example, can lead to an impaired ability to look ahead and plan for the future as a patient may become concerned that they are going to die and thus avoid making any plans for a fear that they will not be around to fulfil them.

## **5.2 – Consequences of living with and beyond cancer**

The results presented in this section look at other consequences of a cancer diagnosis which may lead to future disorientation, which emerged from the interviews. The sub-themes outlined in this chapter are: infertility as a consequence of cancer, loss of control, recurrent thoughts related to cancer, anxiety, impact on family life, and physical consequences of cancer.

As with cancer related fears, participants, for the most part, were not directly asked about the consequences of living with and beyond cancer. It was hoped that this would be discussed naturally by participants when answering the question “Please could you talk about your cancer journey?” However, a prompt was included in the schedule to talk about the impact of cancer on your day to day life, and impact on social life, if a participant did not raise this issue. The second interview explored any changes in the impact of cancer

over time, and therefore as with the last chapter, the sub-themes which emerged from each participant's interviews were similar.

### **5.2.1 Infertility as a consequence of cancer treatment**

There is a paucity of literature exploring future disorientation in people living with and beyond cancer. However, those studies which have been conducted have found that infertility concerns can lead to disrupted views of the future especially if the patient has not had the children they had planned (Maughan & Clarke, C. L. 2001; Roberts & Clarke, C. L. 2009). Failure to adapt to a life without the prospect of having any more children can then lead to experiencing future disorientation. Infertility was a consequence of treatment for three of the participants in this study, Rachel, Rob and Lucy. However, like the findings of Roberts and Clarke, C. L., (2009) and Maughan and Clarke, C. L., (2001), this only contributed to feelings of future disorientation when the participant had planned on having children in the future.

Rachel was treated with gynaecological cancer and a significant consequence of her illness came in her inability to have children due to having a hysterectomy. While there was a chance that she could not have children anyway, as her husband had had a vasectomy and subsequently a reversal, the finality of a hysterectomy was very difficult for her to come to terms with. This becomes evident from the quotes below:

*Rachel Int 1 - "Me husband had had a vasectomy and then he had had a reversal and I think it was one of those things where oh it'll... it might happen it might not and we always knew that it mightn't happen, there was more of a chance, but I think it was like the final, the final thing that there was always something in the back of me mind that I thought oh well it will happen"*

*Rachel Int 1 - "There's been a lot of babies in the family recently erm and that's been quite emotional you know... when you're seeing other people you know having them, it's not... well it is a bit jealousy it is a bit but you know I don't like (pause) I don't know how it's eee how... I'm not jealous of them do you know what I mean, I'm over the moon for the family (G – yeah) members but it's like you know why didn't it happen to me you know"*

The first quote highlights that having children is something which Rachel had always envisioned in her future. Despite reduced likelihood of conception due to her husband's vasectomy, she had always maintained hope that she would one day be a mother. Furthermore, numerous members of her family have recently become parents which served to remind her of her own infertility and led to mixed emotions. While she was happy for her relatives that they had become parents, she was left feeling envious that they have been able to have children when she has not. This further emphasises the idea that Rachel had envisioned a future where she had children of her own, and has led to these mixed feelings. Infertility concerns can lead to the experience of future disorientation if a patient is unable to come to terms with a future without having children. This can lead to feelings of distress, and an avoidance of social occasions such as christenings and children's parties which could cause her to become upset.

The quote below highlights that six months further along in her cancer journey, Rachel is still struggling to come to terms with her infertility:

*Rachel Int 2 - "Well he had a vasectomy and then he had a reversal (Grant – okay), see David's got, two, two children (Grant – right) ... in the family at the minute... there's been a lot of babies born, (G – yeah) and erm, last year was they'd asked me brother to be Godfather and somebody else, and I felt really eh, I think it has been getting to me, and, and I got meself really upset about it and erm then I'd said to (husband) well if I hadn't married you I would, well I might have been able to have children, and it was the worst thing that I, you know, I've ever said"*

The above quote suggests that at the time of the second interview Rachel was still struggling to come to terms with the fact that she cannot have children. Something which becomes more salient each time one of her relatives has another child. This suggests that the distress that she felt in relation to not having children of her own was heightened when she came into contact with young children and brings the sense of loss she felt about her own children into focus. This is emphasised when she stated that she became very upset

when thinking about the christening. Furthermore, the above quote begins to suggest that perhaps Rachel felt that no one understood what she was going through, as her relatives would never know how it felt to want to become a mother, only to have that taken away from you. Furthermore, even her husband has had two children from a previous relationship and she perhaps felt that she was facing this alone. The pain that Rachel was experiencing in relation to a loss of her anticipated future, and a feeling that no one understands her pain may have contributed to her display of anger towards her husband. Rachel seemed to blame him to a certain extent for them not having children before her surgery, as she stated that if she had not married him then she might have children by that point. However, she appeared to feel regret at saying this, as she subsequently stated that it was the worst thing she had ever said to him. As was discussed in Chapter 2, in gynaecological cancer patients, facing up to the reality that they cannot have children after treatment is something which can be hard to come to terms with (Maughan and Clarke, C. L., 2001; Roberts and Clarke, C. L., 2009).

Being a father to adult children, Rob did not seem to see infertility as being an issue in the same way that Rachel did. The quotes below suggest that infertility concerns have not caused a disrupted view of his future:

*Rob – Int 1 “Yes, got some damage to me plumbing (Grant – right okay, in what way?) Eh, I don’t ejaculate... apparently it might be, it might be temporary, it might be permanent, can take a couple of years. (Grant – has it had any impact on sort of home life?) No, just accept it, that’s how it is, it’s better to be alive than...”*

*Rob Int 2 – “Nah that’s exactly the same (Grant – it’s exactly the same, do you have any indication of..?) Erm the information I had was it was either temporary or permanent and it appears to be permanent ... it’s not an issue”*

In the first interview Rob discussed how he had been left unable to ejaculate as a consequence of his surgery for colorectal cancer. However, this has only had a minimal effect on his day to day life as he described how he has just accepted it, and saw it is a fair

trade off with being alive. Asked if this has had any impact on his relationship with his wife, Rob stated that it had not. This may be due in part to Rob's age and the fact that he already had adult children. If he and his wife had not had all of the children that they wanted to have, then this may have had more of an impact on their lives. While being informed that the condition may be temporary, the second quote highlights that Rob was still experiencing the same symptom of his surgery six months later, and he felt that the damage may be permanent. Rob continued to cope with this consequence of his cancer and still felt that this had not been an issue in his relationship with his wife. Therefore, it appears that Rob accepted this consequence of his cancer treatment, and adapted well to this change in his life.

The results presented in this sub-theme suggest that the impact of not being able to have children following a hysterectomy is something that Rachel was not been able to come to terms with, describing the impact at both interviews. Furthermore, Rachel herself believed that this was something which will never go away, and as such she had to learn of ways to deal with these feelings, this is discussed in more detail in Chapter 6. Treatment for gynaecological cancers can often have the sort of impact that is observed with Rachel. The other participant in this study who suffered from a gynaecological cancer, Lucy, did not appear to suffer from the same disrupted view of her future in relation to children, as this was not something which she mentioned in either interview. This may be due to the fact that Lucy already has two adult children and, as she was older than Rachel, had realistically had all of the children she was going to have. This potentially lessened the impact of a hysterectomy in this regard; although it may have had other consequences, something which is explored later in this chapter.

Future disorientation in cancer survivors has previously only been studied in female survivors of breast (Brearden, 1997) and gynaecological cancer (Maughan and Clarke, C.



L., 2001; Roberts and Clarke, C. L., 2009). When considering the extracts from Rob above it becomes clear that infertility has the potential to disrupt views of the future for men as well as women. While Rob did not experience future disorientation in relation to his infertility, a younger man who has not had all of the children he had planned may experience future disorientation and encounter similar consequences to Rachel if he fails to adjust.

The results presented here show that concerns around infertility have the potential to cause future disorientation and if patients fail to adapt to this disrupted view of the future it can cause distress. Rachel has been unable to adapt to the fact that she will not be able to have children and this deviation from the future she had envisioned has proved to be particularly distressing for her. Furthermore, the results presented in this sub-theme have addressed the second research objective of this thesis relating to the potential for infertility to lead to future disorientation in men, and suggests that this is a distinct possibility.

### **5.2.2 Loss of control**

A common sub-theme which emerged from the data was a participant's sense of losing control over some aspect of their life as a consequence of their cancer treatment. The findings discussed below highlight that the feelings of losing control may contribute to uncertainty about the future and lead to experience of future disorientation. The results presented in this sub-theme also show that these feelings may change over time as patients progress in their cancer journey:

*Lucy Int 1 - "I can't explain it, I wasn't in control I think that was basically the bottom line, I wasn't controlling any of this it was all being taken out of my hands... Colostomy, nurse came up and I says 'what?' She says we have to mark you just in case. Well honest to God pah me feet again I just had this horrible dread feeling"*

*Lucy Int 2 - "I do get fleeting moments, as I say it's just I've got no control over any of this Grant and I think that's the problem, I'm such a control freak,*

*that I need to know, but there's half of us is thinking, ignorance sometimes is bliss, you know if you don't know then you don't worry about it (Grant – mmmm) you know so, I'm just in turmoil with meself as usual."*

The quote from Lucy's first interview highlights that she felt during her operation, that she had no control over what was going on, which may have led to feelings of uncertainty over her future. These feelings were exacerbated by an apparent lack of awareness of the pre-operative procedure, as she appears to be surprised when the nurse counselled her for a potential stoma. Her surprise is evidenced when she described a feeling of dread relating to the outcome of her surgery, suggesting she had not comprehended that this was a potential consequence of her cancer treatment. There is a degree of contradiction in the second quote, as Lucy stated that while she was a control freak and that she needed to be in control of things, something she thought was causing her problems with her agitation, she also felt that perhaps she would feel less agitated if she did not know as much as she did. This suggests that it is the uncertainty that was causing her feelings of agitation, and therefore knowing less may actually have caused her to feel more agitated.

Rachel also discussed feelings of not being in control at both interviews, as is highlighted below:

*Rachel Int 1 – "I was erm with thr HRT, as soon as I stopped taking the HRT I seemed to lose weight and then been told that I then had to take it again it's made us, it's made us a bit like, I was totally neurotic"*

*Rachel Int 2 - "I was going to write on like a piece of paper and at New Year burn it, and that's it the cancers gone it's all forgotten about, everything, but then we were with (husbands) family and they were, like we hadn't seen one of the daughter in laws, and she was asking loads of questions, (about) the new baby and I'd got meself really upset about it, and I thought it just hadn't gone the way I'd planned it and I just really think I want to draw a line now, forget about like, I'll not forget, never forget about it, but I just want to forget about it now (cancer) and (Grant – yeah) kinda move on."*

The first interview highlights that Rachel was concerned about not having control over her weight due to her treatment after surgery. She felt that when she was on HRT she had no

control over her weight which is reinforced by her being able to lose weight when she stopped taking the HRT. Another factor which may have contributed to her feelings of not being in control is outlined when she said that she was ‘told’ she was going back on her hormone HRT, the use of the word ‘told’ suggests that she feels she has no say in the matter. Like Lucy, these feelings of being out of control seem to have a negative impact on Rachel as she describes feeling neurotic about the prospect of going back on HRT. The second quote provided by Rachel highlights how when something does not go as expected for her then it can be upsetting. She had planned on making a fresh start on New Year’s Day, but because her sister in law started talking about children, presumably bringing her own infertility back into focus, and caused her to become upset. This caused her to abandon her idea of burning the piece of paper as it had not happened how she had planned it. Furthermore, the repeated use of the word forget in the above quote suggests that her cancer is on her mind, and this is possibly contributing to her feelings of being out of control as she cannot get rid of these intrusive negative thoughts. Feelings of not being in control may lead to future disorientation as it can lead to the future that the patient had envisioned no longer being realistic, and if the patient cannot adapt to the change in their future then this can be distressing.

While both of the above participants had expressed a sense of loss of control in both interviews, for John the idea of not being in control was not something which was discussed his first interview. However, the quote below shows that now that he has returned to work he has expressed a concern about a loss of control relating to his stoma, suggesting that these feelings have the potential to arise at any point along the cancer journey:

*John Int 2 - “I would have found it hard going back into catering, just basically if you are wearing a bag when you are serving customers I just wouldn’t of felt right serving customers food, if I could feel me bag filling up sort of thing”*

The language above suggests that John would feel uncomfortable not having control over his bowels while he was at work. While there is no reason why he could not wear a bag while working in catering, his 'feeling uncomfortable' had led him to consider alternatives such as colonic irrigation. This relates back to what was discussed in the fear of the consequences of cancer sub-theme, where there seemed to be a prevailing perception that colostomy bags were unhygienic, or perhaps would produce a smell that others would notice. However, this loss of control had serious consequences for John as he had considered changing his career if the irrigation was not successful. Like Lucy and Rachel, John's feelings of not being in control of an aspect of his life because of his cancer diagnosis contributed to a disrupted view of this future, in his case this was concerns relating to his occupation. However, John appears to have adapted to this change in his life by finding a way of continuing working in his present job while having a stoma. Had John failed to adapt to his new future this may have led to him feeling distressed working in the catering industry. The wearing of a colostomy bag could have resulted in him not being able to return to work or feeling he had to find alternative employment.

In summary, the feeling of being out of control seems to be an issue which is not experienced by all of the patients in this sample. However, for those who do experience feeling out of control, this can lead to distress. While the cause of these feelings of not being in control may not be consistent, the underlying worry of not being in control of their lives does seem to be consistent over the course of the two interviews. Furthermore, the experience of John highlights that these concerns can develop at any point along the cancer journey. Furthermore, referring back to the previous chapter which looked at experience of future disorientation, there appears to be some relationship between feeling a loss of control and experience of future disorientation for a number of the participants. Lucy, and Rachel both have experienced future disorientation to some extent in both interviews, for

Lucy this related to an uncertain future and a belief that she was going to die from cancer at some point in the future. Rachel on the other hand has had to come to terms with the fact that a major aspect of the future she had envisioned with her husband, having children, would now never be realised. Both of these participants have also experienced a sense of a loss of control, this may suggest that feeling out of control can contribute to feelings of future disorientation. This is perhaps best highlighted through the experience of John whose loss of control in relation to having a stoma and how he came to terms with it was directly linked to his sense of future disorientation. As John came to terms with working in the catering industry while having a stoma, he had considered changing career, as he felt that he would not be comfortable having no control over his bowels in this line of work. Having addressed this issue, and found a solution, John no longer has a sense of future disorientation in the second interview, thus highlighting that these feelings can be overcome in certain situations if the patient has a way of addressing them.

The above results suggest that a feeling of losing control can contribute to the experience of future disorientation as it can prevent a patient coming to terms with the loss of the future they had envisioned. This was particularly evident in the example of Rachel's experience at New Year where an attempt to put cancer behind her, and move on, was hindered by her feeling that she had lost control of the situation. The relationship between feeling a lack of control and future disorientation is discussed in more detail in Chapter 7. Furthermore the experience of John begins to show that the use of positive coping strategies can prevent consequences of cancer from causing future disorientation. Coping strategies is explored in more detail in Chapter 6.

### **5.2.3 Recurrent thoughts related to cancer**

A consequence of living with and beyond cancer which emerged from the data set was negative intrusive thoughts related to cancer. This was not a question which was asked

directly of the participant's however, it was something which emerged from a number of interviews. This seemed to be related to the question 'what impact has cancer had on your day to day lives?' In the following section, participant's experiences of cancer related thoughts over a period of six months is explored and related back to experience of future disorientation to see if they are related.

For some participants while recurrent thoughts related to cancer were a persistent problem over the course of the two interviews, its impact appeared to lessen over time as is outlined in the following quotes:

*Rob Int 1 - "Eh I try not to (laughs) just when it comes up if on the tv or like that it reminds you but you just try to put it out of your mind, forget about it and get on with things... It just reminds me of what it could of been, and still could"*

*Rob Int 2 - "Erm you have odd days when you have your little doubts but er most of the time, with the time the memories fade, and just feel better. (Grant – What do you think brings it on then, if you have those odd days where you feel down?) Just being on your own, being bored (laughs) thinking about stuff (cancer)"*

Rob discussed in the first interview that he tried not to think about cancer, however he felt his mind drifted to thoughts about cancer whenever he saw adverts on television. This suggests that he was more tuned in to the word cancer than he realised. The discussion of cancer on television may be bringing these thoughts into focus, whereas before his diagnosis he may not have noticed this as much. The quote above from his second interview seems to suggest that while he was still experiencing recurrent thoughts related to cancer; they are not occurring as often, as he felt that his memories are fading. Therefore, it may be that while recurrent thoughts related to cancer had been a long term issue for Rob, the longer he progressed without cancer returning then the less it played on his mind. However, he also stated that he had 'little doubts' which are brought about when he was on his own, these little doubts may be related back to the fear of recurrence sub-theme where Rob seemed worried about the fact that his cancer was not caused by genetic

factors. The uncertainty about what caused his initial cancer may be feeding these little doubts about whether or not his cancer could return. His uncertainty about cancer recurrence can also be seen in the first quote where he stated that hearing about other people dying from cancer remind him of what could have been.

The following extract may also illustrate that recurrent thoughts related to cancer fade over time:

*John Int 1 - "I tend not to (think about cancer), no I'm quite a positive person, I think and I've got over it... I mean sometimes I feel absolutely really tired and I go to, go to bed, put me head on the pillow and I just wake up and think, I'm not tired at all, so I don't know what that is, it's weird I feel knackered but I just can't sleep sort of thing at times"*

In the above quote, John suggested that he did not tend to think about his cancer since completing his treatment. However later in the interview he discussed feelings of insomnia, going to bed really tired and being unable to sleep. There is evidence in the literature, as discussed in Chapter 2, that cancer related insomnia is related to anxiety (Theobald, 2004). This then suggests that intrusive thoughts about cancer are more prevalent than he realised or was willing to admit and perhaps like Rob, when alone with his thoughts, his mind drifted to these intrusive thoughts. However, in the second interview John made no mention of insomnia nor did he allude to any recurrent thoughts related to cancer. This would suggest like the quotes from Rob above, that this may improve over time.

However, for other participants intrusive thoughts related to cancer can persist over time and have continued to be an issue which affects them on a regular basis. Some of the consequences of recurrent thoughts related to cancer are highlighted in the quotes below:

*Lucy Int 1 - "there's not a day when you don't think 'cancer' to be honest with you... but there is always something that will trigger it off, it will be an ache or a pain... Oh I would have paced that's why, when I picked the word agitation"*

*(G – yeah), it just summed me up, agitated, pacing, angry, I'll be in the house I'd probably be screaming at meself 'come on get a bloody grip', I'd be chain smoking, drink copious amounts of coffee"*

*Lucy Int 2 – "It is in a way like I am trying to ignore it you know because that's how I want, I want to be able to live, and by that being around, to me it's like, just bringing us down all the time making me feel unhappy and miserable"*

The above quotes from Lucy highlight that recurrent thoughts related to cancer seem to have continued over the course of the two interviews and were still something which was a consistent problem for her. In the first interview she described that there was not a day where she did not think about cancer, this can have a negative impact as she described it in terms of agitation. This quote can also be related back to Lucy's feelings of a loss of control, described in the previous sub-theme, when stating 'come on get a bloody grip'. This language suggests that she did not want to feel this agitation related to recurrent cancer thoughts but felt that she could not control it. She also described the methods she uses to try and regain control over her thoughts, by chain smoking and drinking coffee she is perhaps trying to take her mind off cancer. Lucy's second interview points to intrusive thoughts related to cancer still being a regular occurrence for her as she describes it bringing her down all of the time. This suggests that the feelings have not lessened over time and that she feels she is not able to enjoy her life while constantly having these thoughts. The second quote highlights that she continued her efforts to stamp out these thoughts, whereas before she would try and distract herself by smoking or drinking coffee, she had started to try and avoid thoughts related to cancer. However, the literature above has shown that the use of negative coping strategies can actually lead to more anxiety and distress, and coping in this way may not be the best way to prevent these recurrent thoughts about cancer (Llewellyn, McGurk & Weinman, 2007), this is discussed in more detail in Chapter 6.



In some cases however, recurrent thoughts related to cancer seemed to emerge after diagnosis and treatment, suggesting that a specific event may have triggered these thoughts. Geoff had not discussed these thoughts in the first interview. However, the quote below shows that they emerged at some point in the intervening six months:

*Geoff Int 2 - "If you are diagnosed with something like (cancer) then erm there's nothing you can do about it you know, you just say oh well okay I've got the concerns but I've got the appointment now you've got to go through that which isn't great, that's on your mind more than anything else erm, and there's nothing else you can do it's not as if, not as if you know worrying about it is going to change anything"*

In the above quote, Geoff discussed when he felt that he was experiencing symptoms which had led to concerns of cancer recurrence, something which had occurred at some point between the two interviews. This quote highlights that for those participants who did not initially experience recurrent thoughts related to cancer, the occurrence of a specific event can trigger these thoughts later in the cancer journey. This is evidenced when he stated that the thought of his follow up appointment was playing on his mind, even though he knew there was nothing he could do about it until he got his results.

The results presented above suggest that recurrent thoughts related to cancer, while experienced by a number of participants, do not appear to be a consistent problem. These thoughts only seem to occur sporadically throughout a patient's cancer journey in response to certain events or situations. Two of the four participants described above only experienced recurrent thoughts related to their cancer at one of the two interviews, John at the first interview, and Geoff at the second. This would suggest that these thoughts are not a consistent problem. However, the experience of recurrent cancer related thoughts may become an issue for some participants if they cannot dispel them, Lucy, who described these thoughts in both interviews, discussed that they were making her feel miserable.

Recurrent intrusive thoughts about cancer have been found to be associated with poor adjustment to cancer, and may be predictive of pain, depression, fatigue and functional impairment (Dunport, Bower, Stanton & Ganz, 2014). With this present sample, there would appear to be a relationship between recurrent thoughts about cancer and feelings of fatigue and pain and discomfort, this association is explored in more detail in Section 5.2.7. Lucy who experienced intrusive cancer related thoughts in both interviews also described feelings of pain in both interviews, while Rob and John, who only described recurrent thoughts related to cancer in the first interview, also described a reduction in their feelings of fatigue, and pain respectively. Furthermore, recurrent cancer thoughts may be predictive of future disorientation as Lucy demonstrated continuing feelings of future disorientation. Rob and John however saw a reduction in feelings of future disorientation in the second interview, which would suggest that identifying patients who have recurrent thoughts about their cancer could be a useful way of identifying which patients are experiencing future disorientation. The results presented here seem to suggest that recurrent thoughts related to cancer are not directly related to the experience of future disorientation. However, these thoughts appear to be a consequence of functional impairment which does appear to be associated to with a disrupted view of the future, this is discussed in more detail later in later this Chapter (5.2.7).

#### **5.2.4 Anxiety**

A number of participants interviewed for this study discussed that they had feelings of anxiety associated with their cancer. For some participants this was caused by uncertainty, whereas for others it was caused by a fear of losing control. This sub-theme looks at feelings of anxiety expressed by participants in one or both of the interviews, and explores how these feelings have changed over time. Anxiety did not seem to be a consistent

concern for participants as only one participant expressed feelings of anxiety in both interviews; this is discussed in the quotes below:

*Rachel Int 1 - “why didn’t it happen to me you know... and I think that’s what, what started it off with the like the anxiety the you know, well the cancer did that you know and it’s things where it’s been one of those... like in me mind it’s like one of those things, it’s happened it’s over now but then as I say these last few months it’s started to be like well, you know why, did it, not as much why did it happen to me, it’s just like I’m starting to like oh well, no children, emotional, things like that you know”*

*Rachel Int 2 - “We, me and me husband had had we had an argument, and it was like something silly and that’s what started it off, and it was just, chewing and like we talked it over with (CNS) and everything and it wa you know, but then it’s like, me dad hasn’t been very well so that’s been you know, like chewing me a bit”*

Rachel expressed feelings of anxiety in the first interview, however while acknowledging these feelings she seemed unsure about whether they were caused by the cancer diagnosis in general, or specifically her resulting infertility. Her uncertainty is emphasised by repeatedly changing her mind, at first alluding to infertility being the cause of her anxiety when she says ‘why didn’t it happen to me?’ before changing her mind and stating that the cancer diagnosis first triggered her feelings of anxiety. Therefore, it may be that while her initial diagnosis of cancer was the cause of her anxiety, her resulting infertility and the upset this has caused her in relation to her anticipated future may have exacerbated her feelings of anxiety.

The second quote from Rachel suggests that her anxiety may have been related to feelings of not being in control, which was discussed earlier in this chapter. This was evident when she stated that her dad being unwell, something which she had no control over, contributed to her feelings of anxiety. Furthermore, she discussed how an argument with her husband was ‘chewing’ which in the North East of England means something is playing on your mind. This would suggest that family support, or a lack of communication, had a role to play in her feelings of anxiety as if she continued to chew on the argument then it would

suggest that she had not resolved this issue with her husband. This was further supported when she stated that they discussed the argument with her CNS, again suggesting that they had been unable to resolve their argument, which may have contributed to her feelings of anxiety. Both quotes above would suggest that Rachel has multiple sources of her anxiety, and that while her anxiety was a continuous problem for her, the source of her anxiety appeared to change over time. This would suggest that for some participants there may be a need to intervene in order to alleviate any symptoms. Furthermore, Rachel's feelings of anxiety appear to be related to her infertility in some way, and it may be that feelings of anxiety can impact on a patient's ability to adapt to their disrupted view of the future, therefore contributing to the negative outcomes of future disorientation.

However, while Rachel experienced feelings of anxiety over the course of the two interviews, the majority of participants expressed these feelings at only one of the two interviews. Rob discussed these feelings in the first interview, but made no mention of feeling anxious in the second interview:

*Rob Int – 1 “I get a bit anxious if I have an appointment coming up like, I’ve got a scan coming up, gona have a scan, what’s it gona show, you get a bit of anxiety before the scan, then after the scan you’ve got to wait for the results, and then you get a phone call telling you your scan’s okay so takes about a week after your scan to get the phone call, so that week’s a bit hard work “*

The above quote highlights that for Rob his anxiety was related to fear of recurrence, as he felt anxious when a scheduled follow up appointment was approaching. This is highlighted when he said ‘what is it going to show’, suggesting that he was concerned that the scan was going to show something, the thought of which led to feelings of anxiety. However, this quote also highlights that, like many other effects of cancer, feelings of anxiety may not be stable, Rob went on to discuss that while he had feelings of anxiety related to follow up appointments, once he got the results and learnt that they have not found anything then these feelings tended to go away. Therefore if Rob did not have a

scheduled follow up appointment around the time of the second interview, this may be a reason why feelings of anxiety were not discussed.

For a number of participants who had not expressed feelings of anxiety in the first interview, these seemed to develop in the intervening period, as evidenced by the quotes below. Lucy described feelings of anxiety related to the discovery of a new tumour, and the doctor's asking her to come in for an appointment when she was out of the country. For Geoff his anxiety also seemed to be associated with uncertainty, as he described that the closer he got to his colonoscopy the more worried he became that they were going to find something:

*Lucy Int 2 - "Well, when I was in America? (Grant – ahuh), erm well panicked you know, felt anxiety, felt the pit in me stomach straight away and then of course he's explaining it and I'm thinking right okay, you know, oh why the urgency then if it's alright then so you know you start thinking the worst case scenario"*

*Geoff Int 2 - "The colonoscopy put me mind at rest pretty much (yeah) erm no beforehand, I mean as it got closer to the colonoscopy and the symptoms have been going on for 13 or 14 weeks now erm you're more or less convincing yourself that you're in trouble"*

The above quote from Lucy highlights that uncertainty contributed to her feelings of anxiety, as at first she was asked if she could come in the next day, and after the doctor learned she was in America he told her just to come in when she was back. This led to her worrying why they wanted to see her so soon, if it was not urgent. This uncertainty caused her to think of the 'worst case scenario' and the fact that she would not know why they wanted to see her until she returned from America perhaps further contributed to her anxiety. The quote from Geoff shows that at the time of the second interview he was not as concerned about the possibility of recurrence as he had been at some point in the past. This is evidenced when he discussed the colonoscopy putting his mind at rest, suggesting that before the colonoscopy he had been concerned about the possibility. This relates back

to the point made in the previous sub-theme; that the colonoscopy appointment was causing intrusive thoughts about cancer recurrence and suggests that while the build-up to these appointments may cause anxiety and recurrent cancer thoughts, getting told that there is no sign of the cancer can alleviate these feelings for a period of time.

The literature review reported in Chapter 2.8 highlighted that anxiety is a common consequence of cancer, and that fear of recurrence is seen as a cause of anxiety in patients living with and beyond cancer (Handschel et al, 2012; Hong et al, 2010). This would also appear to be the case with the present sample. As described above, Rachel expressed fears of recurrence in both the first and the second interviews, which seemed to coincide with feelings of anxiety; believing in fact that the thought of recurrence when she found a lump on her breast is what triggered her anxiety. Rob also talked about experiencing fear of recurrence prior to the first interview, and described feelings of anxiety as well, which had only recently stopped being an issue. In his second interview he had not suffered a recurrence of anxiety and may still have been experiencing fears of recurrence although this was not explicitly expressed. Furthermore, Geoff experienced fear of recurrence and feelings of anxiety in the second interview but not the first interview. Lucy was the only exception, as she experienced fear of recurrence in the first interview but did not express feelings of anxiety; in the second interview she began to feel anxious in relation to results from a scan, which may have indicated cancer recurrence. By the time of the second interview Lucy had had her results which showed that indeed it was a new tumour. This resulted in her fear of recurrence developing into fears of cancer progression however, the initial onset of the anxiety still seemed to coincide with fear of recurrence. Sarah and Rob while not explicitly expressing that they were suffering from anxiety, in their second interviews, did mention that they felt nervous around the time of follow up appointments. This further emphasises that there may be a link between fear of recurrence and anxiety, as

each follow up appointment presents a new opportunity for the doctors to find signs of recurrence.

Furthermore, the experience of anxiety may also contribute to feelings of future disorientation; those participants who expressed feelings of anxiety in one or both of the interviews showed signs of future disorientation in the same interviews. Lucy again was the only exception as she only expressed feelings of anxiety in the first interview, but seemed to be experiencing future disorientation in both. As discussed in the literature review, there was a suggestion that fear of recurrence may be related to the experience of future disorientation by causing a disrupted view of a patient's future. The above results suggest that anxiety may moderate this relationship, as fear of recurrence may cause feelings of anxiety, or feelings of anxiety related to follow up appointments may heighten fear of recurrence. This may result in a patient feeling uncomfortable making plans for their future.

#### **5.2.5 Impact on family life**

Over the course of the two interviews a number of participants expressed concerns about the impact that cancer had had on their family members, or their relationships with them. This seemed to be a consistent worry for those patients affected and was expressed in both interviews.

Lucy has had cancer on a previous occasion, and she felt that she had not received the same level of support from her partner on this occasion as she had had when diagnosed with breast cancer. However, she does feel that the support would be there if she asked for it:

*Lucy Int 1 - "I mean the last time he was saying things like 'I don't want to lose you' and all of this, this time he's saying you know 'It'll be alright', but I know it's impacted on him and in a way I think eee bless him you know we've only been together 9 year and 8 of those 9 year he's had me with flippin cancer twice you know and trying to stay positive and he just says I really don't know*

*what to say or what to do. And I can understand that in a way you know, but if I want the cuddles, I have to ask”*

*Lucy Int 2 – “Well as I say there is this unspoken, sort of erm, (pause), atmosphere if you like (G – mmmm), not really talking about it, I mean I think they are dreading Thursday as much as I am erm, as I’ve said to you earlier, I’m more concerned about how they feel, about the situation, I feel guilty in a respect that I’m putting them through this again”*

In the first interview Lucy seemed to feel that her family were not as understanding of her cancer as they had been the first time she had been diagnosed. The above quote suggests that she felt that having cancer twice had negatively impacted on her partner, and may be the reason why he was not as openly supportive as had previously been. The lack of supportive behaviour from her partner was emphasised by him saying he “doesn’t know what to do” indicating that he was not sure how to react this time around. However, the quote also indicates a lack of communication on both sides as if Lucy wanted a cuddle she had to ask for one. This would suggest that she wanted her partner to be more understanding and know when she needed a cuddle rather than having to ask.

In the second interview Lucy discussed how she and her family no longer spoke about her cancer, she stated in her first interview that her partner did not know what to say or what to do and it seems as though this has continued. This seemed to be causing an atmosphere and adding to Lucy’s feelings of uncertainty, as she ‘thinks they are dreading’ her follow up appointment suggesting they had not spoken about how they felt and what the potential outcomes of the follow up would be. This is another situation where Lucy felt she had no control over, saying she felt guilty for putting them through her cancer, and perhaps she was reluctant to take control of the situation and discuss her thoughts and feelings with them, for fear of causing them pain.

Lack of communication also seems to be a factor affecting the impact that cancer has had on Geoff’s family, as outlined in the following quotes:



*Geoff Int 1 - "Me wife actually was quite strange erm it was almost as if it never knocked her out of her stride... I get the impression that she struggled to cope with it, she struggled to come to terms with it and sometimes when people are like that they can be quite argumentative they can be dismissive of it erm one of the things that she actually said; I mean she regrets it now but one of the things that she said at the time was, during an argument she says 'well wha... whats your problem your mother beat and she was older than you'"*

*Geoff Int 2 - "I think other people beside us who don't have it, don't know what you are going through, don't know what you are thinking, they struggle more, I think your family struggle more than you do when they've been in amongst it and it's not till you've come out of it weeks later and you think Jesus Christ that was going on and you start panicking again"*

In the first interview Geoff described the impact that cancer had on his relationship with his wife, this seemed to be caused by avoidance of thinking about cancer and his wife trying to carry on as normal. However, this tended to lead to arguments between them and Geoff felt that his wife's avoidance was a sign that she was struggling to come to terms with what they were going through. He felt that at first she was quite dismissive about his cancer, feeling that if his mother could come through her diagnosis then there was no reason why he should not. However, this may also suggest a lack of communication between the pair about how cancer was affecting them, as Geoff stated that he was under the impression that it never knocked her out of her stride. This suggests that they had not discussed it and this lack of communication and understanding about what impact it had had on each of them may have been contributing to their arguments.

In the second interview Geoff was still concerned about the impact of cancer on his family and he expressed that he felt that cancer actually impacted on them more than it had on him. However, this quote again highlights that a lack of communication may be contributing to the impact on his family, he discussed how he felt that it impacted on them more because they did not know what he was going through or what he was thinking. This would suggest that he was not sharing his thoughts or feelings around cancer with them.

Therefore if Geoff were to be more open about his experiences with his family this may serve to lessen the impact on the family as a whole.

Rachel's inability to have children is a common factor in a lot of the themes discussed in this chapter, and it appears to also have had a negative impact on her family life:

*Rachel Int 1 - "I can't really say to (husband) because... I mean we do talk about it and we have been talking about it a lot, a lot more since I've been coming here (clinic), because it's like, I don't want him to feel that it's partly his fault... you know like his fault as well sort of"*

*Rachel Int 2 - "I don't know whether we spoke about this the last time erm, we hadn't had sex since the operation because we both had like worries about it... Because of the problems that we'd, we had with our sex life erm, I'd taken, like taken like, I'd taken the day off cause... David had brought up something where we work erm, I get up at 6 and you know and, I get up at 5 to go to work, erm David's you, like when I've always worked like really early and everything, and this one day I thought well I'm going to take like the day off in the middle of the week, and see whether it makes any difference and he got up and didn't even acknowledge me and it really upset me"*

In the first interview Rachel gave the impression that she felt she could not openly talk about the impact of her infertility with her husband, worried that he blamed himself. This is explained later in the interview when she said that her husband had had a vasectomy after having two children in a previous relationship, although he did have a reversal in a bid to have children with Rachel prior to her diagnosis. As discussed with Geoff and Lucy communication appears to be a major factor associated with the impact cancer has on family life. Rachel however, appeared to have taken steps to remedy this as she began bringing her husband to follow up appointments with her, which led to them talking things through more. However, by the second interview a lack of communication between Rachel and her husband around her cancer was still having an impact on their relationship. Rachel discussed that she and her husband had not been sexually active since her operation as they both had concerns about what affect it would have on her. However, Rachel had decided one day to take the day off and see if that led to them having sex before her husband went

to work. She then described that she got upset with him when he woke up and just got up and went to work. While this is a good example of Rachel taking control of a situation in order to address her concerns, it highlights that there was still a lack of communication between them which was having a negative impact on their relationship.

The results of this sub-theme highlight that a cancer diagnosis does not just impact on the patient, but can also have an adverse impact on their families as well. A common factor in the above quotes is a lack of communication, with Geoff, Lucy and Rachel all discussing that there had been periods where they were not communicating effectively with their family. This seems to have had a negative impact on their relationships with their close family members. Unlike most of the sub-themes presented within this theme, the impact of cancer on the family seemed to be fairly consistent, as it is discussed by the same participants at both interviews, and is perhaps an area which needs to be looked at further. As discussed in the literature review, a lack of communication with family members may be connected to cancer related fears, with breast cancer patients unwilling to discuss cancer with their children in case the topic of death came up (Walsh et al, 2005). This may also be the case with the participants discussed above, as each of them expressed cancer related fears in both of the interviews. Like the recurrent thoughts related to cancer sub-theme presented above, there does not appear to be a direct link between impact on family life and future disorientation. However, a lack of communication between patients and their families does appear to centre around cancer related fears and the impact of cancer treatment. For Rachel and Lucy this seemed to contribute to their feelings of anxiety which, as discussed above, may reduce their capacity to adapt to their disrupted view of the future.

### 5.2.6 Occupational Impact

In the literature review chapter, evidence looking at the impact that a cancer diagnosis can have on the working lives of patient's was explored. Participants were not directly asked about this impact in the interview schedule, however it was hoped that this would be discussed in relation to the question "what impact has cancer had on your day to day life?" It was felt that any occupational impact may impact on future disorientation, especially ability to make future plans, due to the financial implications if a patient felt unable to return to work. Any issues around employment which arose in the first interviews were discussed with participants in the second interview, to see if there had been any development in their situation.

All of the male participants in this study discussed their future employment, or retirement plans to some degree, with some expressing concerns about their ability to return to work following treatment for cancer. Furthermore, the only female participant still working at the time of the interviews also expressed some concerns related to her career. The quotes below will highlight that for the most part these concerns were not something which were consistently expressed by participants over the course of the two interviews, with the exception of John:

In the below quotes John's concerns about the impact which cancer would have on his career appear to have changed in the six months between the first and second interviews. Prior to returning to work he was concerned about possibly being made redundant, and not wanting to work in the catering industry with a stoma. However, six months later he is back working in the industry, and has adapted well to his stoma, although he does still have concerns and has had to adapt some aspects of his working routine:

*John Int 1 - "So I'm expecting it as soon as I go back to get, like me three months notice, I might not I don't know so I'll just take that as it comes, I was*

*thinking about a career change or a step in a different direction anyway with it being like what I've got now, like the colostomy and everything but there, this has probably pushed us in the other direction to look for something different"*

*John Int 2 – "Fine, I mean since the irrigation, since I started doing the irrigation and it's been absolutely brilliant, to be honest if I had of had the bag like I would have found, that was one of me big concerns if I had, if the irrigation hadn't of worked or anything like that I think I would have found it hard going back into catering... I mean I try not to do any heavy lifting as such like, I use trolleys and stuff rather, I mean, times before hand I would of just lugged a without, any heavy weights ...one of me bigger concerns is in the future for, cause that's, they like hernias could be a big problem"*

In the first interview John had serious concerns about his future employment, with a number of redundancies at his place of work he believed that he would be given notice of the termination of his employment. John also appeared to have concerns about whether or not he wanted to continue working in the same industry, as he a catering manager he was concerned about having a stoma and using a colostomy bag in that environment. There is a degree of uncertainty in this quote as John talked about probably moving in a different direction career wise, and how he was unsure whether or not he would receive his notice period. This could suggest that he would rather not have changed career, but the uncertainty over his redundancy and whether or not he would have felt comfortable wearing a bag over his stoma was causing him to question his future career. As time progressed John continued to work in the same industry, as evidenced in the second extract above. In order to combat his concerns about returning to work with a colostomy bag over his stoma he took the decision to irrigate the stoma at home, thus self-managing his symptoms. John adjusted well to doing the irrigation; describing it as brilliant and he believed it was the main reason why he had not pursued another career. However, he had to make other adjustments to his working routine, as he no longer felt comfortable lifting heavy weights as he was concerned about it leading to hernias in the future. The above quotes from John suggest that evolving occupational concerns can lead to the experience of future disorientation. As John adapted to having a stoma, and learned how to continue

working in the catering industry, his concerns about his employment decreased. The result of this was he no longer felt it necessary to look for another career, and was no longer experiencing any negative outcomes of future disorientation such as financial concerns or an inability to plan for the future.

While John expressed concerns about the impact cancer could have on his career at both interviews, suggesting that these feelings may be consistent over time, this was not the case for most of the other participants in this sample. The participants below expressed concerns only in the first interview however, as stated above, Paul was not available for the second interview, and therefore the long term impact on his career could not be ascertained:

*Paul Int 1 - "I cannae see us going back to work cause I'm 65 in February but eh if they were wanting us back I'll go back I'm not bothered cause I'm still fit enough... well I felt a bit tired at first... I mean it's only natural because eh I'd only been what... they look after us for the first month, fairly easy and then they said right you get into the hard work I says champion I want to (laughs). It wasn't hard work, just walking with a cutting machine, cutting grass its nought you know no problem."*

*Rob Int 1 - "Devastating at first cause I retired at 57 a week after me 57<sup>th</sup> birthday and I'm thinking fantastic, I've got 25 years of retirement to do whatever I want, and 2 and a half years later I'm having surgery for bowel cancer. Which I was just, completely flattened us"*

The above quote from Paul highlights that he was concerned that because of his age, he would not be able to return to his job as a gardener for the council. When he stated that 'if they are wanting us back,' this highlights his concerns that his bosses did not want him to come back to work. This is further emphasised when he discussed still being fit enough to work, suggesting that retirement would not have been his choice. However, later in the interview Paul discussed feeling quite tired when he returned to work the last time, and he contradicted himself when he said that he went back to the hard work, but then says it was not hard, only cutting grass. This could suggest that Paul found the work harder than he

had in the past, and found that it was tiring him out. Therefore when Paul stated that his bosses might not have wanted him to return to work, this may reflect his own personal feelings that the work was tiring him more than it used to before his surgery and he did not feel fit enough to return to work. Like John, Paul appeared to have concerns about returning to work after his surgery and this may have led to feelings of future disorientation in terms of the financial implications of not being in employment.

The quote from Rob's first interview suggests that not only can the impact of cancer lead to future occupational concerns, but it can also impact on future retirement plans. Rob demonstrated how strongly he felt that cancer has impacted on the life he had envisioned post-retirement through use of the words 'devastated' and 'flattened'. The reason he may have felt so strongly about this was highlighted when he said that he had imagined having 25 years of being able to do whatever he wanted to do once he retired, and he felt that this was no longer possible. However, as time progressed the impact on Rob's retirement seems to have lessened, as in the second interview he discussed looking forward to his wife retiring so that they could do whatever they wanted. This may indicate that as he had adapted to his cancer diagnosis, he became more comfortable planning for his future in line with how he envisioned it before his diagnosis. However, the change in his attitude towards planning for the future may also have been prompted by the imminent retirement of his wife, which will have afforded them the opportunity to spend more time with one another.

Furthermore, like Paul and Rob above, the following participants only expressed concerns about their occupation at one time point, in this case it was the second interview:

*Geoff Int 2 - "It was erm constant diarrhoea but diarrhoea as much as you're not going every time, or it's just every time you do go. Erm and what I was having to do was, I was having to take tablets to stop eh I work part-time Thursday, Friday, Saturday, Sunday, got into a routine where on a Thursday*

*morning I would take the tablets to stop the situation erm and then by Monday, I'd stop taking the tablets on Sunday, by Monday or Tuesday the tablets would come out of our body and go whoosh. So whether or not there was a little case of getting into that cycle prolonged the symptoms"*

*Rachel Int 2 - "If anything went wrong or worrying that I wasn't go(od), wasn't able to do it, it, I was very anxious but then this other job came up which was a lot more stressful (Grant – mmmm) and me manager decided that I should do that, that was the help that she give me (Grant – to give you a more stressful job?) Yes, ahuh but in my mind, in my mind it was like has she given this job to get us from, like away from that job"*

In the last interview Geoff did not explicitly express concerns about his future employment in terms of his cancer, however since he experienced his symptoms he has had to make some adjustments to lessen the impact on his working life. Geoff was concerned about the impact that diarrhoea would have on his job, so he began taking medication to ease the symptoms, allowing him to continue working as normal. However, the symptoms lasted longer than Geoff had anticipated, the above quote highlighting that he felt that taking the medication in such a routine way had actually prolonged his symptoms. This may tie into the fear of recurrence and uncertainty, discussed earlier in relation to Geoff. Diarrhoea was a symptom which first led to Geoff's diagnosis and its return, and the length of time he suffered, may have contributed to his fear of recurrence. When Geoff was told that the diarrhoea was not a symptom of cancer recurrence he was left uncertain as to what was causing it. This may be why he believed that the medication was prolonging his symptoms, as he searched for a reason for him experiencing them for so long. Like John, the nature of Geoff's work may have contributed to the impact of cancer on his working life. Whereas John worked in catering, and felt unhygienic wearing a colostomy bag, Geoff works as a delivery driver, and spends a large portion of his day without access to a toilet. The uncontrollable nature of his symptoms would therefore make it difficult to function effectively at work. Unlike John, Geoff did not discuss any intention to change his career and this is perhaps due to him finding a solution to his problem, had he not done



this then it is possible that his concerns may have developed into future disorientation, and a feeling that he would have to change career.

Rachel expressed concern that she would not be able to do her job as well as she had before taking time off to recover, these concerns being compounded when she was moved to a different department. Even though it was to a more difficult job, which her bosses felt she could do, Rachel felt that it was because she was not good enough, and she thought her boss just wanted to get rid of her. This further highlights the issues that Rachel has had around anxiety since her operation, as what should have been seen as a vote of confidence and a promotion at work, was instead seen as confirmation that she was not doing her job properly. These feelings were not expressed by Rachel in the first interview, which may be because she had not developed these feelings yet, or it may be that being moved to a new position either brought on these feelings, or caused them to become more salient.

In summary, while initially there appeared to be sex differences in the impact that cancer can have on a patient's employment after the first interview, where only male participants expressed these concerns, this no longer appears to be the case. While all of the male participants did express concerns about the impact of cancer on their employment, compared to just one female participant, it should be noted that of the eight participants, three of the male participants were still working at the time of the interviews compared to just one female participant. Rather than sex shaping the occupational impact of cancer, there seems to be fluctuations in its impact over time. Of the five participants who expressed occupational concerns, only John seemed to have consistent concerns about his working life, which may be due to the fact that he had a permanent stoma as a consequence of his surgery. The other participants seemed to have fluctuating concerns, suggesting that the impact can worsen or lessen over time, depending on individual circumstances.

The results presented above seem to support the literature on the impact of a cancer diagnosis on a patient's occupation, as discussed in Chapter 2. Reasons presented by Amir, H. et al (2011), suggest that financial pressures and a desire to return to normality may be the reasons why patients are keen to return to their working life. Charmaz (1994) however, suggests that functional impairment, in relation to treatment, may act as a barrier to people wanting to return to work. This seems to be the case with Paul, John, and Geoff. As Geoff had recently been made redundant before his diagnosis, there may have been a desire to get back to earning money as soon as possible. Likewise for Paul, feeling that his bosses at the council may not have wanted to keep him on for the next year, he may have been keen to prove to them that he was still capable of doing the job. John on the other hand suffered functional impairment in relation to his stoma, and the potential need to wear a colostomy bag made him wary of returning to work in the same industry. However, after beginning irrigating his stoma, rather than wearing a bag, he became more comfortable continuing to work in the catering industry. The experience of John would also suggest that if a patient addresses their employment concerns then this can help to alleviate feelings of future disorientation, and they can return to planning for their future.

The above results also indicate that the impact of cancer on a patient's working life may contribute to feelings of future disorientation. While John was able to find a solution that allowed him to continue in his current occupation, his concern about working in a catering environment with a stoma highlights that if he was unable to adapt, then this may have led to him seeking alternative employment. The resulting financial insecurity related to this can then cause a disruption to his previously held view of the future, and make planning for the future difficult.

### 5.2.7 Physical consequences

On-going pain and discomfort following treatment for cancer is something which was discussed by a number of participants in this study. While for the most part this seemed to improve with time, the following quotes show that it can become a long term concern for patients:

*Lucy Int 1 – “I was getting pains and discomfort again in the stomach and, I... I wasn’t sure if that was a sign so I rang up and she said we’ll get you back in to see (consultant) and we’ll have you know see what he says so he sent me for another scan and that was fine”*

*Lucy Int 2 - “I just erm focus in on, I get windy pains here, I get crampy pains here, I mean they’ve said I can get pains from the stent... but I mean the flu didn’t help, that totally felled me and made me think oh my God you know, I had nothing, I had no energy for nothing, I just feel blunt, I don’t get a... I used to get a buzz about doing stuff”*

The extract from Lucy’s first interview emphasises that one of the consequences of experiencing pain and discomfort after cancer treatment is that it may lead to thoughts of cancer recurrence. While Lucy does not state that she thought the cancer had returned, her fear of recurrence has been highlighted earlier in this thesis. Furthermore when she stated that she was not sure if this was a sign, followed by contacting her consultant to have a scan, it would appear that the pain she felt contributed to her fear of recurrence and led to seeking reassurance from her consultant. The second interview highlights that Lucy was still suffering from feelings of pain and discomfort, which did not seem to improve with time. The listing of symptoms in the above quote seems to suggest that Lucy felt that things were starting to get on top of her, as the symptoms she was experiencing began to accumulate. This seemed to be having an effect on her mood when she said ‘I used to get a buzz out of doing stuff’ which would suggest that she was no longer experiencing this buzz, or level of enjoyment out of life. This was also evident in the first interview when she said that she had felt that she was going along side of life rather than living it, although those feelings had started to fade, the impact of finding another tumour may have brought

these back into focus. Lucy has expressed fear that she is going to die because of her cancer, and facing the prospect having cancer for a third time may be contributing to her physical symptoms and the feeling that she has no energy.

Similarly to Lucy, the quotes from Geoff below suggests the experiences of pain and discomfort can lead a patient to believe that they are experiencing symptoms of cancer recurrence:

*Geoff Int 1 - "I'd had a lot of problems two days before it because I'd been given a lot of pain killers an nobody bothered telling us erm that they would make you constipated. Now the nature of the operation they should of really given us something to counteract that, woke up on the Wednesday morning and the pain was incredible and the wound burst and there was a lot of gunge coming out and down me leg and everything and a... a... I lay on the bed and the immediate thought I had was I was gonna die"*

*Geoff Int 2 - "Sometimes yeah er sometimes it reminds you that, yeah, not so much now, but certainly the first year or two it did erm you could turn the wrong way or you could you know do something and it, it reminds you that it's there. That's the, the sort of erm, twinges where its, more in the stomach"*

While with Lucy, an association between pain and discomfort and fear of recurrence begins to emerge, the above quotes from Geoff suggest that the association may be related to the severity and context of the pain. While in some cases a prolonged experience of aches and pains may be associated with recurrence, a single experience of severe pain could even lead to thoughts of death. This is evident in the first quote from Geoff, which was discussed earlier in the results section, where a single episode of extreme pain caused Geoff to believe that he was dying. In the second interview while Geoff was still experiencing pain, this did not seem to be as severe, describing them as twinge. This may be contributing to his fear of recurrence, which was brought on by the experience of similar symptoms which lead to his initial diagnosis. When Geoff stated that the aches, 'reminds you that it's there' this suggests that his mind comes back to cancer whenever he experiences these twinges, prolonged exposure to which may have led him to believe that his cancer had recurred.

While he discussed that he did not experience these twinges often, he did say that he had had them for the first couple of years after his surgery. If they have always made him think his cancer had returned then this would suggest that Geoff had been experiencing fear of recurrence for much longer than he had stated. However, he may not have associated these pains with recurrence until he had the experience of sensations which led him to believe that his cancer had recurred. This may have caused him to re-evaluate these aches and twinges that he had been experiencing for so long. This would again suggest that fear of recurrence is not a stable construct, and that a number of factors can lead to a patient being concerned that their cancer will recur.

However, feelings of pain and discomfort were not necessarily a permanent consequence of surgery for cancer, and as time goes on the discomfort may ease, as is evidenced in the following quotes:

*John Int 1 – “Just for extra painkillers and I’m pretty much got them still and I’m only pretty much taking them if I’m in the car for any length of time, if I’m sitting for like half an hour at a time, it’s basically just like sitting on a golf ball rather than being uncomfortable eh uncomfortable rather than sore”*

*John Int 2 - “yeah I’ve been brilliant, like I say working down in Darlington, like 35-40 miles each day, each way and it’s absolutely spot on, we, went down to (pause), where’d we go, great Yarmouth on the bus on like national holidays sat for like 6 hours on a bus and that didn’t bother me”*

*Paul Int 1 - “Even through the night it was really good if I were... in a bit of pain I’d sht gives a tablet just get us a paracetamol and knock us back to sleep and I was alright. Mhmm”*

In the first interview John described feelings of discomfort in his buttocks and lower back whenever he sat down for prolonged periods of time, especially in the car. He likened this to a feeling of sitting on a golf ball which he said was not painful but uncomfortable. As with the previous sub-theme where John was using irrigation to manage his stoma with relation to his working life, the results presented in this sub-theme suggest that he was using medication to manage these feelings of discomfort. However, while John expressed

that he did not find the experience painful, he seemed to be saving his painkillers for when he needed to make long journeys in the car. This would suggest that he is experiencing some level of pain to require him to take painkillers to manage it. A transition is evident in John's experience of pain and discomfort in the six months between interviews when looking at the second quote. Due to his new job he was now spending a significant amount of time in the car, which was originally the source of his discomfort, but he seemed to be coping well with the prolonged periods of time sitting down. The change in his experience of discomfort is highlighted when he talked about spending six hours on a bus trip, something which would have been inconceivable six months ago. This would suggest that the discomfort he felt was only a temporary consequence of his cancer surgery and may have been linked to his wound healing. Furthermore, while data from only one interview was collected from Paul, the above quote, like the examples from John, does begin to show that aches and pains may begin to ease off as a patient moves through their cancer journey. In his quote he discussed being in a bit of pain after his operation which was managed by the clinical team using painkillers. However, he made no mention of aches and pains or twinges, common to most other participants in this sample, at any time after his initial surgery, although he did mention that he found his work to be tiring him out more now than it had before.

Another area where cancer can affect patients after their treatment is that it can leave them feeling less physically fit than they used to; this is highlighted in the quotes below:

*Geoff Int 1 – “Erm, the one thing that I’ve noticed is, th... that I never got back was the stamina or strength that I had... probably me fittest was actually when I had the tumour which sounds stupid er but at the time I was going to the gym and I was like er... had a feeling of wellbeing and I was actually feeling quite fit for... for me at that time... I tried to go back to the gym about a year later and I never got it back again I’ve never got the stamina levels... I get exhausted very, I don’t think I’ll ever get back to the levels I was, stamina wise”*

*Geoff Int 2 – “I was also a bit lethargic as well, feeling tired all of the time, physically, but I have been generally since I was ill anyway, I’ve never had the stamina that I’ve had.”*

The first quote highlights that Geoff noticed a change in his physical fitness since he had his operation, describing that while he felt at his fittest just before he was diagnosed, he had never recovered this level of stamina. While he did attempt to regain his fitness by going to the gym, he described feeling exhausted by the physical exertion, and stopped going. However, given that he waited a year before returning to the gym, it is understandable that his level of fitness would have dropped, and perhaps had he continued to push himself he may have been able to regain some degree of fitness. In the second interview, six months later, Geoff still felt that his stamina levels had never returned. This would suggest that feeling lethargic is a long term consequence of his surgery, and in order to avoid feeling exhausted he continued his avoidance of physical exertion. Feelings of fatigue during cancer treatment have been reported widely in the literature (Ream, Davidson & Evison, 2005; Thong et al, 2013) and patients can continue to feel fatigued long after they have completed treatment for cancer (Jacobson & Stein, 1999; Jensen, Houborg, Norager, Henriksen, & Laurberg, 2001). Feeling less physically fit after treatment for cancer was a common experience, and was also discussed by Paul, Lindsay, and Rob:

*Paul Int 1 - “When I got back to work, I was tired at first, first couple of weeks”*

*Lindsay Int 1 - “It’s slowed us down more, it’s slowed me down after the lung operation, but the bowel operation slowed us down even more”*

*Rob Int 1 – “I mean walking, 5 minute walk to the paper shop to get a paper, I was absolutely wrecked”*

Unlike the other participants, Rob began to regain a feeling of physical well-being, as discussed in the recovery sub-theme, after increasing his level of physical activity. This

suggests that an exercise intervention may help participants overcome these feelings of exhaustion after physically exerting themselves.

In light of the results outlined above it would appear that physical complaints such as pain and discomfort, and feelings of lethargy, are common amongst people living with and beyond cancer. For the majority of participants, these symptoms did not appear to improve over time, as Lucy and Geoff both discussed continued feelings of pain in both of their interviews. Furthermore, Geoff and Lindsay discussed feeling lethargic in both interviews. However, this was not the case for everyone, as while John experienced pain related to his surgery in the first interview, by the time of the second interview the pain had stopped. Likewise, Rob who had expressed feeling physically tired if he walked for five minutes to the shop in the first interview, had started exercising more and felt physically fitter by the time of the second interview. There appears to be a strong association between experience of pain and discomfort, and fear of recurrence, however the nature of this relationship is not clear. It may be that pain and discomfort can lead to fears of recurrence which seems to be the case with Lucy. However, with Geoff the relationship may be the other way around, as even though he has experienced twinges and pains for more than two years, he has only recently started to think of them in terms of recurrence. This is possibly related to the experience of what he thought were symptoms of recurrence, highlighting that the relationships between pain and discomfort and fear of recurrence may be cyclical. For other patients, who did not explicitly express fears of recurrence, their experience of pain which they discussed in the first interview, was not a concern that was repeated in the second one, suggesting that these pains may have eased off in the intervening period.

The results here support the evidence in the literature that not all patients will experience cancer related pain with prevalence being reported by between 42%-56% of patients (Breivik et al, 2009; MacFarlane et al, 2012; Miaskowski & Dibble, 1995). Furthermore



the evidence presented by Breivik et al (2009) suggests that the experience of pain for cancer patients is something which is on-going, which was the case for Lucy and Geoff. Additionally, a loss of stamina following treatment for cancer has also been discussed in the literature, with Cella, Davis, Breitbart, and Curt (2001) reporting that on-going cancer related fatigue following treatment for cancer was reported by 33% of participants. The experience of Geoff, and Lindsay, reported above would support this, as they reported feeling a loss of stamina consistently across both interviews. However, Rob seemed to regain his stamina following a concerted effort to improve his diet, and increase his levels of physical activity. This suggests that a physical exercise intervention may help patients overcome feelings of fatigue or loss of stamina which could result in reduced fear of recurrence and subsequently, reduced future disorientation.

### **5.2.8 Summary**

In summary, the results presented in the above chapter highlight that a cancer diagnosis, and subsequent treatment, can impact on a patient's life in a multitude of ways. Certain impacts of cancer such as, the negative impact on family life, or concerns about infertility, may be long term consequences of cancer treatment, as they were discussed by the same participants at both of their interviews. Other impacts of cancer such as anxiety, or the experience of pain and discomfort on the other hand may begin to improve over time. For some participants who described feelings of anxiety, or pain, in the first interview this was no longer an issue in the second interview. For those patients, who described feeling anxious, or who were still experiencing pain, there seemed to be a reduction in the experience, suggesting that they felt an improvement in their recovery.

The results above also highlight an association between the outcomes of future disorientation and the various impacts of cancer. As when a participant described the negative impacts of cancer in one of their two interviews, they usually also discussed a

negative impact of future disorientation, which suggests that impacts of cancer may contribute to a failure to adapt to a new view of the future. For the male participant's in this study there seemed to be a particular association with occupational impact, and future disorientation, as all of these participants discussed occupational concerns in conjunction with the experience of future disorientation. Physical consequences were also discussed in these interviews, with Paul and Geoff in particular mentioning physical consequences such as, the experience of pain, in direct relation to their occupations. As discussed in the literature chapter, financial pressures can lead to patients' desire to return to work (Amir, H. et al 2011), and feeling pain or fatigue while working, may lead to concerns that they are unable to do as good a job as before. This could then disrupt a patient's view of the future as they try to come to terms with the thought that they may have to seek alternative employment, and if a patient is unable to return to their previous employment, or find alternative employment, this could exacerbate financial concerns and make it difficult to plan for a new future.

While impacts of cancer did not seem to be consistent for the male participants in this study, this was not the case for Rachel and Lucy, both of whom had issues around feelings of anxiety, a lack of communication of cancer concerns with their significant others, and feeling out of control, all of which they experienced in both the first and second interviews. In addition to this, Rachel and Lucy also experienced feelings of future disorientation in both the first and second interviews, suggesting that the continued experience of negative impacts of cancer may be why future disorientation is a persistent problem for them, when it does not appear to be so for the male participants. However; as the male participants in this study did also experience some continuous negative impacts of cancer, it is possible that certain consequences of cancer are more likely to induce continuous feelings of future disorientation. For Rachel, who's future disorientation seems to stem from infertility,

difficulty coming to terms with the fact that she will not be able to have children of her own seems to be the driving force of her future disorientation. Employment issues on the other hand seem to be the main cause of future disorientation for the male participants in this study. Lucy on the other hand seems to be more effected by cancer related fears, as her future disorientation seems to stem from feelings of an uncertain future. In summary, this results presented in this theme suggest that negative consequences of cancer are a common occurrence across sex and tumour location. However, the impact of these consequences seem to affect female participants for longer, given that they are more likely to discuss them in both interviews. Furthermore, different impacts of cancer, and possibly a combination of them, seem to be associated with feelings of future disorientation.

The above results relate to the second research objective of this study which sought to identify a number of factors which may cause future disorientation. A number of factors were identified in the literature review that could lead to future disorientation such as anxiety, occupational concerns and concerns around infertility. While there is no clear relationship between the experience of anxiety and future disorientation the evidence above certainly points to the fact that infertility, and occupational concerns have the potential to cause future disorientation in both males and females, and can lead to negative outcomes if a patient is unable to come to terms with a new sense of their future. The possibility that positive coping strategies and functional support may limit the consequences of future disorientation was discussed in the literature review, and this is explored in more detail in the next results chapter.

## **Chapter 6 – Coping with life after treatment**

The first results chapter in this thesis outlined the relationship between the consequence of cancer and cancer treatment, and future disorientation. This chapter explores factors emerging from the interviews which may prevent or ameliorate future disorientation, for example, coping strategies and support, and how they may change over time. Sub-themes which emerged from the interviews and are presented in this chapter are: making sense of symptoms; lifestyle adjustments; psychological/emotional adjustments; information seeking; religious/spiritual coping; hope; taking control; formal support; and social support.

Participants were asked directly in the interview to discuss levels of support they have received since finishing their treatment, both in terms of family and friends, as well as the clinical support they have received from the NHS. This was asked of participants due to support being identified in the literature as a protective factor in the experience of stressful life circumstances (Bloom & Spiegel, 1984). Participants were also asked directly about their coping strategies through the questions “Do you have any difficult days?” and “How do you manage them?” Coping strategies were identified in the literature review as being able to predict which patients will develop cancer related fears (Llewellyn, McGurk & Weinman, 2007), furthermore adaptive coping strategies were shown to be associated with lower anxiety (Cousson-Gelie et al 2007) and therefore coping strategies may be an important factor in reducing negative outcomes of experiencing future disorientation.

### **6.1 Making sense of symptoms**

The way in which patients made sense of their symptoms before and after their initial diagnosis varied from one participant to another. Some participants ignored their initial symptoms believing them to be caused by pre-existing medical conditions, and this

continued when experiencing potential symptoms of cancer after their initial treatment. Others believed their symptoms were indicative of cancer and reported them to a GP as soon as possible:

*Geoff Int 1 - "Woke up on the Thursday morning em to notice that through the night I'd been leaking blood, it's bowel cancer I had erm obviously didn't know at the time I'd just been leaking blood em that went on for about three days and went away so I just put it down to haemorrhoids. About 10 days later a similar thing happened again where I was leaking blood... because I've got a family history of bowel cancer erm I arranged an appointment with the doctor"*

*Geoff Int 2 - "I had some symptoms, it lasted about three months which did cause concern and obviously when erm whe... when you've had something like I've had, whe... when there's something not right you immediately think 'oh it's back' and it, it, it's difficult not to think that way."*

In the first interview it is clear that before initial diagnosis, Geoff attributed his symptoms to haemorrhoids, but later in the quote Geoff discusses a family history of colorectal cancer which eventually led to him getting his symptoms checked out by a GP. Given this history it is perhaps surprising that he waited so long to get his symptoms checked out. His family history of colorectal cancer however may be the reason why he waited to see if the symptoms would go away on their own, for fear of being told by the doctor that it was cancer. Evidence in the literature in this regard is mixed. Bostean, Cresps and McCarthy (2013) found that family history of site specific cancer increased uptake of colorectal cancer screening in men and breast cancer screening in women. However, Ponce et al (2011) found that Latino Americans were less likely to attend screenings for colorectal cancer when they had a family history of cancer. However, Llewellyn, Weinman, McGurk, and Humphris (2008) found that avoidance coping was actually linked to the experience of fear of recurrence, and by not reporting his symptoms Geoff may be prolonging the negative experience of fear of recurrence. This would suggest that factors other than family history may be responsible for delays in symptom reporting.

At some stage between the two interviews, Geoff experienced similar symptoms again, however this time he made sense of his symptoms by attributing them to a recurrence of his cancer. What is interesting to note here is that even though Geoff states that he immediately thought it was back (referring to his cancer) he still waited to report his symptoms to his CNS; stating later in the interview that he waited 8 weeks before reporting them to her. He explains the delay in reporting his symptoms by saying they were not as severe as his original symptoms, however he still attributed these symptoms to cancer and avoided reporting them. This links with his fear of recurrence and is something which appeared to be the case for a number of participants, where they are afraid to have their suspicions confirmed. Therefore, even when patients attribute their symptoms to cancer and are concerned about these symptoms there can still be a reluctance to report them. The use of avoidance as a coping strategy may result in a failure to adapt to a disrupted view of the future. This may then lead to negative outcomes such as an impaired ability to plan for the future as Geoff discussed considering cancelling a holiday he had booked when he was concerned that he would have to undergo surgery for recurrent cancer.

Like Geoff, John had attributed his original symptoms to a pre-existing medical condition, however he reported his symptoms to his GP straight away. As illustrated in these quotes, his attitude towards reporting possible symptoms has changed over time:

*John Int 1 - "I went to the doctor after I had blood when I went to the toilet eh I'd had quite, blood for quite a while, erm basically I just put it down to had, had me gall bladder out a couple of years ago"*

*John Int 2 - "The only thing was, er when I came back on Monday and Tuesday, I had a few pains and aches and I don't know if I had a slight blockage or something... I had one occasion where I thought I had a blockage... but it was just like quite a bit of pain lower down... like really bad pains and it was like cramp pains, and I had a feeling when I looked on the research and that like it had said it could be a blockage... so I just eat like roughage and stuff like that, brown bread and what have you, just try and ease it up a bit... it was fine after a couple of days, and it was a similar sort of pain this time"*

In the first quote John, like Geoff, had attributed his condition to a pre-existing medical condition, which caused a delay in his reporting them to a doctor, as evidenced when he stated that he ‘had blood for quite a while’. Later in the interview John also discusses having a family member who had been diagnosed with colorectal cancer, and like Geoff, this may have led to concern that this was what was causing their symptoms and a reluctance to have these suspicions confirmed. In the second interview we can see that despite experiencing symptoms related to his stoma on two occasions, he has not reported these to his CNS. Referring back to the fear of recurrence sub-theme, John stated that he would not know what the symptoms would be if he did suffer a recurrence, therefore it is perhaps this uncertainty which led him to wait and see if they eased on their own. In the second quote above, John states that after doing some research online he believed that his pain was caused by a blockage due to eating too much food while he was on a recent holiday. Rather than report his pain, therefore, he waited to see if it would subside on its own, which it did. This may help explain his avoidance to report his symptoms as he appears to have found a logical cause for them. While John also avoided reporting his symptoms to his CNS, he does appear to have adopted a problem focussed coping strategy. This is something which he also did when it came to managing his stoma, by researching what may have caused his symptoms and attempting to self-manage the symptoms, something which resulted in his symptoms easing off.

The examples laid out above highlight that despite a previous diagnosis of cancer, patients can still be reluctant to report the experience of any new symptoms to a medical professional. This appears to be the case whether they feel that the symptoms may indicate a recurrence of cancer or not. This suggests that avoiding reporting symptoms may be a form of coping with fear of recurrence as if they do not report their symptoms then they cannot have their suspicions confirmed.

In contrast to this, however, some patients may take the opposite approach, reporting any symptoms to their GP as soon as possible:

*Lucy Int 1 - "I got what was pains in the abdomen, back in last year which was what 2011 em went to the GPs I knew it wasn't a water infection even though they tried to fob me off, I was just so insistent that they sent me for a pelvic scan and I just had this gut feeling... my psyche was telling me something was wrong"*

*Lucy Int 2 - "I'd started getting these pains and things again, well the pains have never really gone away, me abdomen and stuff like that and they have just poo pooed it (I – mmmm) as Dr Smith decided to send us for another scan, and here, it was showing some lesions and shadows and stuff, er, me lower kidney, me right kidney area, stomach, in between the stomach and the pancreas was a little sort of tumour"*

The first quote above highlights that Lucy did not attribute her symptoms to a pre-existing medical condition and was convinced that it was a sign of cancer. While she was subsequently diagnosed with ovarian cancer, it should be noted that Lucy had previously had breast cancer before the first interview and therefore this may have influenced her decision to go to the doctor so quickly. Furthermore, even when her doctor told her it was just a urine infection, Lucy was convinced it was cancer and persisted until she eventually had her diagnosis confirmed. The different approach to Lucy making sense of her symptoms when compared to John and Geoff may also be associated to fear of recurrence. However, whilst John and Geoff implicitly implied a fear of recurrence in their second interviews, Lucy explicitly expressed these fears in both of her interviews. This may then explain why she was keen to get her symptoms checked by a doctor. The second quote above highlights that after the first interview Lucy has again experienced what she thought were symptoms of cancer recurrence, this time, pains in her abdomen. She has continued to react to these symptoms in the same way, by reporting them to a doctor when she has concerns. However, like the last time she felt that the doctors did not have the same concerns as her, describing them as 'poo-pooing' her symptoms, attributing them to adhesions. However, Lucy again convinced her consultant to send her for a scan, which



showed that she had in fact developed a new tumour on her kidneys. The results presented here highlight that how a patient makes sense of their symptoms does not necessarily relate to whether or not they will actually report these symptoms to a doctor, or a CNS, both before their initial diagnosis and after. What seems to be more important is whether or not the patient felt that their initial symptoms were caused by cancer. Both Geoff and John initially attributed their symptoms to a pre-existing medical condition, haemorrhoids (Geoff), and having a gall bladder removed (John), and both delayed reporting these symptoms to a GP. Furthermore, after treatment both of these patients had an episode where they were experiencing symptoms which may have been an indication of recurrence. Even though Geoff attributed his symptoms to a possible recurrence, he still waited months to report them to his CNS. Alternatively, John did not believe it to be a sign of recurrence and did not report them to his CNS at all. Lucy on the other hand felt that the symptoms she experienced before being diagnosed were indicative of cancer and asked to be screened. When she felt that she was experiencing new symptoms after the first interview, she also reported them to her GP straight away.

Referring back to the fear of recurrence sub-theme (5.1.1), there may be a relationship between how a patient makes sense of their symptoms, whether or not they report these symptoms and their experience of fear of recurrence. Those participants who attributed their symptoms to pre-existing conditions seemed much less likely to have expressed a fear of recurrence than those who believed that their symptoms were cancer, however the relationship is unclear. Fear of recurrence may lead to patients attributing symptoms to cancer, or it may be that believing symptoms are indicative of cancer leads to fear of recurrence. This is consistent with the findings of Llewellyn et al (2008), who found that illness representations were predictive of which head and neck cancer survivors would develop fears of recurrence.

## 6.2 Lifestyle Adjustments

The following sub-theme describes adjustments that participants have made to their lives following treatment for cancer, and whether or not these adjustments have become a permanent feature of their lives now that they are living with and beyond cancer:

*John Int 1 – “Well, I mean I’ve, I went out for the first time on Saturday night gone, that was just like a family do eh it was me sisters, eh me wife’s sisters 70<sup>th</sup> birthday and that was just like a few hours in the pub and a bit of a get together sort of thing eh I haven’t been out that much since then but like since the operation obviously I’ve been like in too much pain and been taking painkillers”*

*Rachel Int 1 – “I couldn’t drink erm, used to have a couple of glasses of wine and I was feeling sickly so that was the only real for me, erm social life no nothing really, nothing really changed.”*

In the first interviews, both John and Rachel had made some adjustment to their social lives after their treatment for cancer. For John, he had avoided going out with friends and socialising as he was still in pain from his operation, although at the time of the interview he had just had his first night out since his operation. However, while he avoided going out because he was in pain, the above quote would suggest that his avoidance of social situations is only temporary, and he is beginning to feel more able to go out and do things. Rachel on the other hand, did not avoid social situations as she felt that nothing had changed with respect to her social life. However, she did feel unable to consume alcohol as it made her feel nauseous. Furthermore, while she was still socialising to the same extent as before her diagnosis, in the last chapter it emerged that she finds it difficult to attend social situations. This reinforced her childlessness, subsequently causing her distress as she was reminded that she face a future without the children she had always envisioned would be part of her life with her husband.

In the second interviews with John and Rachel, there has been a progression in their social lives in the intervening six months, suggesting that some lifestyle adjustments are only temporary coping measures:

*John Int 2 – “Yeah we go out regularly, we go out for meals couple of times a week and what have you down the local pub I’ve been out with friends out in the town and what have you, it’s just no problem at all now, just go out when I feel like it basically, just nothing stopping, I just tend to do the irrigation, so it like coincides with us going out”*

*Rachel Int 2 – “I was the life and soul of the party, you know and we used to have a good, I used to have a good laugh and everything, you know where for the last couple of years I’ve just been, I’ve, we would go to a family party at me cousins and I would be the one that’s sat in the conservatory just having a drink and not wanting to join in you know where before it was like oh you know like I’d be playing with the kids”*

The above quotes show that John has adjusted to living with his stoma and feels more comfortable going on nights out. This can be related to the previous chapter where John’s experience of pain was described and how he no longer experiences the pain and discomfort he had felt just after his operation. John has had to make a lifestyle adjustment in terms of planning for nights out, however, as he states that he does his irrigation coinciding with a night out. This is a method of cleaning his stoma without wearing a colostomy bag, something which he does once or twice a week. This would suggest that he feels more comfortable going out with a completely empty bowel and needs prior notice of plans so that he can plan his irrigation, and would perhaps be adverse to spur of the moment plans which may involve him going out with a full bowel.

In the above quote Rachel discusses drinking at parties and how she no longer feels nauseous when she drinks alcohol, suggesting that this reaction was only a temporary consequence of her cancer. However, six months further into her cancer journey she still finds it difficult to attend parties or family gatherings where there are young children present. In order to prevent herself from getting upset she usually avoids the children by

sitting in the conservatory, whereas before she feels that she would have been playing with the kids and joining in activities. Looking back at the previous chapter this coping strategy can be attributed to her belief that the feelings associated with not being able to have children will never go away. Therefore as long as these feelings remain salient, then she will find a way of coping with these feelings, such as avoiding situations where she will be around young children. Rachel feels that her family do not fully understand why she finds it difficult being around children, and this issue is explored in more detail in the social support sub-theme (6.9).

However, for other participants there was a positive change in their social activities after treatment for cancer:

*Paul Int 1 – “I mean I don’t drink as much now as I used to I’m only going the (pub) once a week now... I mean I like going out for meals me and the wife we like Italians, Indians somewhere different. Yeah, mmmm oh aye, looking on life different to what I did then”*

*Sarah Int 1 – “Funny enough since this happened I’ve started to take me grandchildren away for, on, national holidays for weekends and we enjoy ourselves”*

*Sarah Int 2 – “I said if it’s alright after me colonoscopy (I – yeah) then I’ll book another trip away for us (grandchildren)”*

The above quotes highlight that there can also be positive lifestyle adjustments made after a cancer diagnosis in terms of a patient’s social life. While John and Rachel initially encountered a reduction in their social activities, Paul and Sarah have started to spend more time with their families. Paul was unavailable for the second interview and it is not possible to determine whether or not this change would have continued, as was the case with Sarah. However, there appears to be a relationship between Sarah’s increased time with her family and fear of recurrence and future disorientation by looking at the second quote. While she enjoys spending more time with her grandchildren, when she has a clinical appointment coming up she seems to hold back on making plans, this would

suggest that due to fear of recurrence she does not want to make plans before the appointment in case something shows up.

In summary, the patients in this study have made various adjustments to their lives following treatment for cancer. These adjustments may be something which continues post treatment, or it may have been a temporary adjustment while they were adapting to living with and beyond cancer. A common factor which arose amongst the participants was a change to their social lives. This could be a reduction in social activities as seen in Rachel and John, or it could be an increase in social activities, like spending more time with their families, which was the case with Sarah and Paul. The experience of Rachel and John would suggest that they have made these adjustments to cope with impacts of cancer which were discussed in the previous chapter. While Rachel and John initially seemed to reduce how much they socialised, this seemed to improve over the course of the two interviews, although the reasons for the change in their social activities were somewhat different. The initial reluctance for John to socialise was due to the proximity of the interview to his operation, therefore he was still recovering and was still experiencing pain in his lower back and backside after the operation, and was perhaps still adapting to living with a stoma. Once the pain had dissipated and he had learned to plan his social activities around irrigation, he became more comfortable socialising. Rachel on the other hand still socialised with friends after her operation but did not drink as much alcohol as before as she felt that it made her feel nauseated, However, this seemed to fade with time and she now feels able to enjoy alcohol again without this side effect. At the same time, Rachel still avoids certain social situations where there will be young children as this can still upset her as it reminds her that she cannot have children of her own. Avoidance of situations which may remind a patient of cancer has been shown to be a symptom of post-traumatic stress disorder and may be indicative of poor adjustment to living with and

beyond cancer (Kwekkeboom, & Seng, 2002). The above examples would suggest that lifestyle adjustments arise as a response to an impact which cancer has had on their lives and serves as a way of coping with them. Furthermore, the impact of cancer and how they cope can influence how well a patient adjusts to their disrupted view of the future.

### **6.3 Psychological and emotional adjustments**

The following sub-theme details ways in which participants feel that they have adapted psychologically and emotionally to a diagnosis of cancer. Some participants felt that they were less emotional post-diagnosis than they were before, while others used avoidance as a way of coping, by putting any thoughts of cancer to the back of their minds. For the most part these coping mechanisms tended to be fairly consistent and discussed in both interviews.

Avoiding thinking about cancer after finishing treatment was discussed by a number of participants in this study, and was something which they continued to do over the course of both interviews. However, this could lead to negative consequences, as evidenced below:

*John Int 1 – “I tend not to, no I’m quite a positive person, I think and I’ve got over it, they’ve said I got the all clear straight away. No I just tend to put everything to the back of me mind, I mean obviously I think about it a little bit but just doesn’t affect us day to day life at all.”*

*John Int 2 – “I mean it wouldn’t have any like negative way that I act sort of thing wouldn’t like knock us back or anything like that, would just put it in the back of me mind, does make you think when you hear like the negative things, but (I – mhmm) I would just put it to the back of me mind”*

As stated previously, avoidance seemed to be a common coping mechanism employed by participants and has been discussed in relation to fear of recurrence and making sense of symptoms. This suggests that there is a connection between avoidance coping, and cancer related fears (Llewellyn et al. 2007). In the above quotes from John we can see that avoidance can be used when it comes to a patient attempting to move on with their lives

and trying to forget about their cancer. In the first quote John has made a concerted effort not to think about his cancer diagnosis, although he admits that he still thinks about his cancer diagnosis from time to time, although it is not a persistent problem. However, as discussed in the last chapter, around this time John was feeling fatigued and suffering from insomnia, factors which can be symptomatic of anxiety and related to avoidance coping (Dunport, et al, 2014). This could mean that John worries about his cancer more than he realises, and that pushing it to the back of his mind and failing to address these concerns may be contributing to his insomnia. In the quote from John's second interview he is discussing how he did not want to talk to any previous patient's about their experience of colorectal cancer as he did not want to hear any negative stories. Again, John states that if he heard any negative experiences of colorectal cancer it would not impact on him, and he would put it to the back of his mind. This suggests that John is still employing avoidance as a coping strategy to deal with negative thoughts about cancer. However he did not discuss feelings of fatigue and insomnia at his second interview, so while his coping strategy has remained stable, his feelings of anxiety may have faded over time. This highlights that patients may adopt a number of coping strategies, as John has previously talked about quite positive problem focussing coping strategies in relation to his stoma and occupational concerns which seemed to have reduced the impact of his future disorientation. Therefore had he taken the same approach and addressed any negative thoughts he had had about cancer then this may have helped with his feelings of fatigue and insomnia.

Another way in which participants can adjust their lives after a cancer diagnosis is through changes in how they express their emotions. This can either be a conscious effort to suppress their feelings or it can be an involuntary response:

*Lucy Int 1 – “It was like I couldn’t cry, I wouldn’t allow myself to cry em I just carried on and thought right okay you know this is a bigger and harder one... I just bottled everything up basically and then just blew, blew a gasket (pause). One night, with friends just opened up and let the, you know emotions out”*

*Rachel Int 1 – “me emotions just, you know, it was like erm, didn’t cry, didn’t you know, it’s only, it’s only probablies the last few months where I’ve, I’ve actually got me tears back”*

The above quotes show that emotional suppression can occur as a consequence of a cancer diagnosis. For Lucy, the suppression of her emotions may have been related to the fact that this was her second cancer diagnosis. When she says that she felt this was a “bigger, harder one”, this suggests that she felt that she needed to focus all of her time and energy on beating it and getting back to where she was before diagnosis. However, as seen with John, this suppression may have negative consequences. Rachel describes that one night her emotions got the better of her and she “blew a gasket” suggesting that all of her emotions and negative feelings were expressed at once.

Rachel also appears to have had issues expressing her emotions since her diagnosis. However there is a suggestion that Rachel did not make the same conscious effort to suppress them as Lucy did. When she says that in the last few months she been able to cry again, this could indicate that she had not wanted to suppress her emotions, and this is evidenced in the second interview:

*Rachel Int 2 – “I got meself upset and I cried and I thought, oh, but it lasted like, a second if that (I – mmmm), you know and then it’s I still can’t cry as much, I’m more emotional and, but now I think it’s more instead of where I would, have a really good cry and that was it, that would be it, I, I, I would the anxiety starts”*

*Lucy Int 2 – “so I started a diary... I just you know, would update, but everything about it was, it was just getting out feeling like shite, the doctors were this, tablets, can’t get nought right it, you know and in the end, I think it was after I did the creative writing thing with (CNS) I just stopped, I thought, I’m tormenting myself even more here, or maybe I’m not acknowledging it, cause by writing it down I was acknowledging how I was feeling, I was getting it out”*



The above quote demonstrates that six months later Rachel is still having issues expressing her emotions, and there is a sense in this quote that she feels that crying is not necessarily a bad thing and may be a way of addressing negative emotions. This is highlighted when she says she used 'to have a good cry, and that was it', the use of the word "good" here may have a double meaning, pointing to a belief that crying can be a positive way of dealing with her emotions, and 'that is it' indicating that once she had had a good cry she could move on. Good may also be related to the duration of her crying, with 'good' indicating that it lasted for a long time, with the short duration of her crying events now not being long enough to deal with her emotions. Like Lucy and John above, not addressing negative emotions whether through avoidance or suppression can have a negative impact for Rachel's who feels that it may be contributing to her feelings of anxiety, something which is supported by the literature (Llewellyn et al 2007).

Whereas with Lucy, in the first interview she discussed how she had only started being able to cry again, but in the above quote we can see that she appears to be unsure how best to express her negative emotions. On one hand she says that she is aware that by expressing them she is probably acknowledging them and letting go of them. However, on the other hand, she feels that by acknowledging any negative emotions she is tormenting herself. As with the sub-theme above Impact on Family Life (5.2.5) there appears to be a link between a lack of communication and talking about how you are feeling with family members, and the negative impact it can have in terms of feelings of anxiety. The above interview extracts suggest that coping strategies could be associated with future disorientation, with positive coping strategies reducing the negative outcomes of future disorientation, and negative coping strategies exacerbating disrupted views of the future. Rachel and Lucy allude to feelings of future disorientation in both interviews and have both adopted similar coping strategies in the form of avoidance, and appear to be

suppressing their emotions. John on the other hand, while expressing feelings of future disorientation in the first interview, has subsequently adopted a problem focussed coping approach and these feelings seemed to have eased over time.

A coping mechanism which was discussed in the second interviews by some participants was distraction. Participants' felt that when they were alone or bored, this caused them to think about their cancer experience, and they therefore try and keep themselves busy to avoid this. An example of this is provided in the quote below:

*Lucy Int 2 – "When I'm busy and I'm occupied, I'm fine (I – yeah), erm that's why I've pushed meself to go back to the, me keep fit classes and me little working job and things like that, it's when I've got nothing to do and I'm sitting, erm, I just focus in on (cancer)"*

The above quote suggests that when a participant has nothing to occupy their mind then their thoughts can drift back to their cancer. 'I've pushed meself to go back to the, me keep fit classes', this highlights that negative thoughts can happen at any time but particularly if people are not engaged in activities that serve as distraction.

Another area of a participant's life which they may need to adapt to after cancer is changes in their sex lives. This particular topic can impact on patients in a number of ways and as such, has been discussed in various themes throughout this thesis. Depending on the tumour location cancer can have a varied impact on the participant's sex life, and how they adapt to this impact is also variable.

Rachel and Lucy only discussed changes in their sex life following treatment for cancer at the second interview. The following quotes show that physical changes are not the only reason why participants may experience an adjustment to their sex lives after a cancer diagnosis:

*Rachel Int 2 – “We hadn’t had sex since the operation because we both had like worries about it, you know erm so obviously (CNS) has been, is seeing me husband with me now you know and you know obviously trying to help us through that which you know it has progressed a little bit”*

*Lucy Int 2 – “Having to have a colostomy would be just another nail in the coffin to me. As regards femininity, and sort of feeling sexual I suppose, yeah, I mean that’s out the window now at the minute, and I don’t think (partner) understands that either, bless him, oh dear”*

The above quotes highlight that patients can have concerns about their sex life after a cancer diagnosis for a number of different reasons, and that these concerns may not always be consistent. Rachel’s quote highlights that despite only mentioning that she has not resumed sexual intercourse with her husband at the second interview, this had been the case ever since her operation. Rachel feels that both she and her husband have concerns about resuming sexual activity. While she does not discuss what these concerns are, it may relate to the nature of her treatment which involved invasive surgery in the form of a hysterectomy. Like many aspects of her recovery from cancer, Rachel has taken control of these issues by bringing her husband along to clinical appointments with her CNS to try and get to a place where they both feel comfortable having sex again. As described in the previous chapter, Rachel and her husband seemed to have some difficulties communicating their cancer concerns to each other, and in fact she discussed how this lack of communication had caused an argument around trying to re-engage in sexual intercourse.

While for Rachel the impact on their sex life seems to have been immediate, this does not appear to be the case for Lucy. In the second interview Lucy gave reasons why she was glad she did not have to have a stoma and colostomy bag after her surgery. One of the reasons was the negative impact this procedure would have on her body image and feeling sexual. She goes on to say that ‘that is out of the window at the minute’ suggesting that at the time of the interview she was not engaging in sexual intercourse with her partner. Like Rachel there seems to be a degree of non-communication between her and her partner

around this issue as she states that ‘I don’t think he understands that’ this would appear to suggest that they have not discussed why she is not feeling sexual. While Lucy did not discuss changes to her sex life in the first interview, unlike Rachel there is no indication that this has been a long term impact, instead when she says ‘out of the window at the minute’ this gives the impression that this is a relatively recent development and may be related to the discovery of the tumour at her last scan.

The examples provided above could all be described as relatively negative coping strategies, as the participants appear to be adopting avoidance and emotional suppression as a way of adapting to their lives beyond cancer. The impact of negative coping strategies was discussed in the literature review and is predictive of anxiety (Norberg, Lindblad & Boman, 2005). This link between negative coping strategies and anxiety appears to be present with the patients described above. Rachel and Lucy both described feelings of anxiety in both interviews, and John also discussed feelings of insomnia, which is linked to anxiety (Theobald, 2004) and intrusive thoughts. While it cannot be ascertained whether or not the use of avoidance coping is responsible for feelings of anxiety with these patients, it may be a contributing factor, and suggests that this is something which could be discussed with patients before treatment commences in an effort to reduce feelings of anxiety.

The impact of cancer can be far reaching, and it may also lead in a change to the sexual activity of patient’s with their partners. This particular adjustment appears only to have been a concern to participants in this study who had been diagnosed with gynaecological cancers, and was not discussed by any of the colorectal cancer participants. Both Rachel and Lucy had a hysterectomy as a result of their cancer treatment and since then both have discussed issues around engaging in sexual contact with their partners. Rachel discussed not having sexual intercourse with her husband following treatment for cervical cancer, which reflects the findings of previous studies showing shown that adverse sexual

functioning is a common occurrence in this population (Gruman, Robertson, Hacker & Sommer, 2001). Further, other research has also shown that psychosexual interventions delivered by a CSN can improve sexual functioning amongst gynaecological cancer survivors (Maughan and Clarke, 2001). Therefore, this would suggest that by discussing these issues with her CNS, Rachel is moving in the right direction to address these issues. However, as discussed, another barrier to improved sexual functioning appears to be a lack of communication with her partner, and this would also need to be addressed in order to re-establish sexual activity with her husband. Lucy on the other hand does not discuss whether or not this is an issue she has discussed with her CNS, but like Rachel she appears to not be communicating her concerns about sexual activity with her partner, and this may be contributing to a continued lack of sexual activity.

#### **6.4 Religion/Spirituality**

Cancer is a life threatening illness and can be seen as a significant and perhaps traumatic life event, as well as something which patients have very little control over. Therefore some may employ religious coping methods as a way of feeling grounded. People who were not religious before may start praying or going to church, while others may turn away from religion completely. The results below will look to see if these feelings were consistently expressed over time. The participants in this study who described religion, or spirituality, as a coping mechanism appeared to employ either a collaborative or deferring approach. This was looked at in more detail in Chapter 2.5. A collaborative approach sees the patient and God as partners who are both responsible for their recovery whereas a deferring approach sees God as solely responsible. However, the approach used can vary over time, as outlined below.

For Lindsay, there has been a continued use of religion as a way of feeling grounded, even though she still would not class herself as religious. This is explored in the quotes below:

*Lindsay Int 1 – “Yeah, but definitely changes you, and I’ve never prayed as much in me life as I have over the last seven years, em and I never really believed in angels. But as you see there’s three there (points), I’ve got one, and I’ve got others in the unit. It’s funny how an illness can change your life”*

*Lindsay Int 2 – “I do believe that is what got me through erm was my guardian angel, and I’m not really religious, I do believe in God but I don’t go to church er, but I still believe in angels and I do believe that is something after death... I hope there is because that has kept me going”*

In the first quote, Lindsay discusses how she has started to use guardian angels almost as a way of protecting her from harm. This may have arisen when her husband gave her a guardian angel necklace as she was recovering from cancer, and since then she has acquired a number of guardian angel statuettes which she keeps in her house. The change in her spirituality since she was diagnosed with cancer is further highlighted when she states that she has never prayed so much in her life, suggesting an increase in her practicing of religion since she was diagnosed with cancer. This may be related to feelings of uncertainty associated with cancer and, as a patient’s future life expectancy is somewhat out of their control, they may turn to religion as a way of coping in the hope that praying will protect them from future harm. The second interview highlights that Lindsay has continued to utilise religion as a method of coping. The importance of this coping mechanism for Lindsay is emphasised when she states that she thinks this is what got her through her cancer journey. Furthermore, the idea of being religious appears to be new to Lindsay, further emphasising that this behaviour has arisen in response to her cancer diagnosis as she describes herself as not being religious, despite stating her belief of God, guardian angels and the afterlife. This may be because she has spent her life not being religious and is perhaps reluctant to start describing herself as such.

However, clear parallels can be drawn between these quotes and the deferring coping mechanism described by Pargament et al (1988). While they described deferring as putting the responsibility of recovering from illness squarely on the shoulders of God, Lindsay still seems to be employing some form of this approach. She describes how they (guardian angels) got her through, suggesting that she feels that they were responsible for her recovery rather than herself. While evidence for the impact on using religion as a method of coping with a cancer diagnosis is mixed, there is some literature which suggests that the use of certain types of religious coping such as deference can reduce feelings of distress and increase adjustment to illness (Thuné-Boyle et al., 2006).

While Lucy also appears to have utilised religion as a method of coping with her cancer diagnosis, there seems to be a reduction on her reliance on religion over time:

*Lucy Int 1 – “I don’t know if I’ve got OCD or a creature of habit or I’m superstitious or what but when I was in a... in a... in a dark place I started saying the lord’s prayer every night before I go to bed and I’m not religious not really, but I have to do that, doesn’t matter where I am, I have to say the lord’s prayer”*

*Lucy Int 2 – “I still do that not as often but I still do cause I’ve, I’ve thought, well what’s the point erm (laughs) cause it hasn’t worked, oh dear, erm... I think because I need hope, I need hope of some description from somewhere and at the moment I don’t feel that anybody is giving me any hope do you know what I mean”*

In the first interview with Lucy she seems to share Lindsay’s reluctance to admit being religious. Again this would highlight that this behaviour is not a normal behaviour for her and has arisen as a response to her cancer diagnosis. Also, like Lindsay, there seems to be a link between feelings of uncertainty over her future life expectancy and praying as she describes starting to say the Lord’s prayer when she was in a ‘dark place’. Lucy described in her interview how she often went to bed at night thinking about whether or not she was going to wake up in the morning, and this may be the ‘dark place’ she was referring to. Therefore the ritual of praying before she went to sleep may have been a way of protecting

herself and ensuring that she did in fact wake up. The second quote again highlights what seems to be an important theme for Lucy, the feeling of uncertainty about how her cancer is progressing. Whereas in the first interview she could use religion and prayers as a way of combating her fears of recurrence, now that her doctors have found a new tumour she feels that her prayers have not been answered and therefore does not think that praying will do her any good. Furthermore, when she says 'no one is giving me any hope' this emphasizes that she does not personally feel hopeful and needs to get her hope externally. Where this used to come from praying she is now looking to get that hope for the future elsewhere. Looking at both interviews as a whole there is a shift in the type of religious coping being adopted by Lucy. She discusses in the second interview that she uses praying as a way of gaining hope for her future that she does not seem to be getting elsewhere. This would suggest that in the first interview Lucy was also using a deference approach to religious coping as she was praying every night when she was worried that she might not wake up in the morning, and saw praying as a way of protecting herself. However, after her cancer recurred, her coping seems to have shifted to a more collaborative approach, as she feels that praying by itself has not protected her. Lucy also states that she still prays, just not as often suggesting that she no longer solely relies on God to protect her but is also looking externally for this hope.

This supports the findings of Nairn and Merluzzi (2003) who found that there was often an overlapping of collaborative and deferring coping styles. However, while they reported that patients adopting these approaches tended to suffer less adverse consequences of cancer than those who used a self-reliance approach, this would not appear to be the case with Lucy and Lindsay who have both experienced anxiety and fear of recurrence. However, as no one discussed using a self-reliance religious coping strategy in this study, then it is not possible to say whether or not Lindsay and Lucy were better off for having



adopted these approaches. However, it should be noted that in their paper, Nairn and Merluzzi (2003) used the religious problem solving scale to identify which method of coping their participants were using, and it is possible that Lindsay and Lucy may not have loaded onto this factor had they completed the scale. This highlights that adopting certain religious coping methods may help to reduce the impact of cancer, and reduce feelings of future disorientation.

## 6.5 Hope

Another coping mechanism which has been discussed by participants was 'hope'. This took various forms such as a hope that cancer does not come back and a hope that their children do not develop cancer in the future. The following quotes highlight how these feelings of hope have remained consistent for participants between the two interviews:

*Geoff Int 1 – “You know obviously I still think about it from time to time; it was a traumatic time erm and I hope it never comes back but I don't sort of erm; I don't (pause). I don't sort of let it get on me mind too much”*

*Geoff Int 2 – “Erm I think it would have been similar in terms of what I have just described, erm I think me options would have been less but that's something that Mr Bell would know and I wouldn't but hopefully I never find out but erm it's on your mind you're thinking well there's only so much they can cut away”*

In the first interview Geoff discusses feelings of hope which are associated with fear of recurrence. While Geoff did not explicitly express fears of recurrence in the first interview he did discuss how he sometimes thought about it from time to time due to the traumatic nature of the experience. By stating that he hopes it does not come back, this suggests that he has experienced fear of recurrence on some level. However this does not appear to be affecting him in a great deal as he describes not letting it get on his mind too much. The second interview shows that his feelings of hope are still focussed on fear of recurrence, and seem to be more explicit. Given that Geoff had recently had a scare where he thought

he was experiencing symptoms of recurrence it is perhaps unsurprising that his thoughts have now turned to how they would treat recurrent cancer. When Geoff says ‘there’s only so much they can cut away’, this may explain why he is concerned about cancer recurrence, suggesting that he is afraid that his prognosis would not be good if the cancer came back. By talking about hope in terms of recurrence, this suggests that he still considers recurrence to be a distinct possibility, perhaps reinforced by his recent experience of potential symptoms.

The relationship between hope and adjustment to cancer has been investigated by Stanton, Danoff-Burg and Huggins (2002). They found that hope alone did not predict better adjustment to cancer, but that high hope combined with high use of religious coping strategies resulted in significantly better adjustment to cancer up to 12-months after diagnosis. The use of positive coping strategies such as acceptance coupled with hope also tended to result in better adjustment. Geoff’s experience seems to support the findings of Stanton et al (2002) as, over the course of the two interviews, his adjustment to cancer does not appear to have improved despite expressing hope at both time points in terms of his chances of cancer recurring. This may then be related to his use of other coping strategies which have tended to be negative such as avoiding reporting symptoms to his CNS and not communicating his concerns with his family. Therefore, by not using effective coping strategies, Geoff has experienced an increase in his fear of recurrence over a six month period which has contributed to his disrupted view of the future. These quotes also emphasise the temporal nature of adjustment to cancer as, while in the first interview Geoff expressed low fear of recurrence and no future disorientation, the onset of symptoms and how Geoff coped with these resulted in a change in his experience of these issues. This is in contrast to Geoff’s method of coping with occupational concerns discussed in Chapter 5.2.6. When experiencing diarrhoea Geoff used a positive problem focussed coping

strategy which reduced his experience of future disorientation which could have led to him seeking alternative employment.

Lucy did not discuss feelings of hope in the first interview and while she does not explicitly express them in the second interview they seem to have developed in the time between the two interviews, as outlined in the quote below:

*Lucy Int 2 – “You know there’s not many folk who survive pancreatic cancer, but if you catch it early enough they can take that away, they can take half me liver away, they can even take me stomach away you know and I can live with one lung, so I’m thinking, well there’ll not be much of us left but (laughs).”*

Lucy did not discuss feelings of hope in the first interview but they seem to have arisen out in response to cancer related fears, in particular her fear that her newly discovered tumour will spread to other areas of her body. Her feelings of hope seem to be related to survival and the hope that if her cancer has spread then it will be caught in time by the doctors so that they will be able to operate. The listing of various areas of her body that she can live without is interesting as it emphasises her fear that the cancer has spread, but by stating there is a chance of survival if they catch it early enough, and that there may not be much of her left, she seems to be clinging on to the hope that she can beat cancer again. As discussed, Stanton et al (2002) found that high hope combined with religious coping could result in better adjustment to cancer. However, like Geoff, Lucy’s adjustment to cancer has not improved over the two interviews, perhaps exacerbated by the discovery of a new tumour. Lucy does not utilise religious coping and hope at the same time, and instead discusses that she used religion as a way of garnering hope that she felt was not coming from elsewhere. Lucy appears to have adopted negative coping strategies such as avoidance, the use of substances (tobacco and caffeine), and emotional suppression in response to her diagnosis of cancer, and while she initially used religion as a way of coping, this has reduced in the second interview.

## 6.6 Formal Support

Campbell, P. et al (2011) differentiate between different kinds of support that patients can draw on. Formal support is that which is offered in a formal setting by health professionals or social services. Any support offered out with these channels is defined as social support.

One source of support which was discussed by participants was the use of formal support services offered by hospitals, such as clinical appointments and regular meetings with a CNS. The level of perceived support that a participant felt they had received since finishing treatment is something which was discussed extensively by participants in both interviews. In the first interview a number of differences in the level of perceived support from clinical staff were observed. The examples below show that the level of perceived support seems to have remained stable even though some participants have moved from three to six monthly appointments:

*John Int 1 – “Eh hospital have been brilliant both beforehand and during the op, hospital stay they always kept us fully, like aware of what was going to happen, how I was doing and it’s been pretty much the same when I’ve come out the hospital”*

*John Int 2 – “Must be September, October the last time I seen them, yeah so I haven’t seen anybody. I haven’t, I mean, I know they’re there, if I need them but I haven’t felt like I’ve needed them for anything basically so...”*

In the first interview John appears happy with the level of support he has received from clinical staff at the hospital where he was treated, and feels that they provided him with the information he needed to deal with his diagnosis and treatment. The matching of information given by health professionals to the level of information a patient wants is well documented in the literature (Williams, K., Beeken, & Wardle, 2013; Williams, P., Nicholas, Huntington, & McClean, 2002), and may be contributing to John’s satisfaction with the support he received. John still seems to be satisfied with the level of formal support he is receiving at the second interview. While the quote above suggests that he

doesn't see the clinical staff very often, as he can't seem to remember when he last seen them, this doesn't seem to bother him as he says he knows they are there if he needs them. As discussed earlier in this chapter, John has had a number of occasions where he has experienced symptoms and pain which he felt may have indicated that his cancer had recurred. However, while John acknowledges that there is support there for him if he needs it, he has opted to try and manage these issues himself through researching online and in time the symptoms have subsided. He also stated that if his symptoms had persisted any longer then he would have consulted a GP or CNS, thus suggesting that he would only use this kind of support if he really needed to. While John has not used functional support from the clinical team to relieve his fear of recurrence, he has still managed to cope with his symptoms by using positive coping strategies and thus a potential source of future disorientation has been avoided.

However, some of the participants in this study did not feel that the level of formal support they received was as good as it could have been. These feeling have also been consistently expressed at both interviews, as evidenced by the below quotes:

*Lucy Int 1 – “The lady I had through at (hospital), Sophie, I found very cold and very calculated, wasn't ringing me up wasn't asking how I was, basically said you know if you've got a problem ring me. The only time she seemed to ring me was when she either had something to ask me to participate in or to give me some information.”*

*Lucy Int 2 – “Dr Soman, who basically wanted me in that day... he thought that I was having chemo, and I says well that's news to me... but Dr Smith had even indicated when I did see him, cause, that's been the problem seeing Davis, Manson, Davis, they're not quite on the same par, but Dr Smith was saying he wouldn't be bothered if, even with this scan if there was slight changes.”*

The quotes above from Lucy show that she was not entirely happy with the level of support she received from the hospital since she was diagnosed with cancer and felt that she had to contact them if she needed support. When she did have contact with her appointed Macmillan nurse she felt that it was very formal, describing it as cold and calculated, and

was never to check how she was feeling. This would suggest that Lucy was feeling a lack of emotional support from her Macmillan nurse which she perhaps felt that she needed. This may have made her reluctant to contact her, feeling that the support should have been offered without her asking. This ties into Lucy's coping mechanisms in general as she seems to utilise negative coping strategies such as avoidance, for example she was reluctant to talk about her cancer with her family or to ask her partner for support when she felt down. However, in both cases she has acknowledged that the support is there if she needs it, so, while Lucy has the option of accessing functional support, due to her tendency to use avoidance, she is not accessing it (Bloom & Spiegel, 1984).

In the second interview Lucy still appears to be unhappy with the type of support that she has received from her clinical team, this time however it is in relation to follow up appointments. Lucy has expressed feelings of anxiety in both interviews which seem to be related to uncertainty and cancer related fears, the above quotes show that her follow up appointments may be contributing to these feelings. Not seeing the same consultant at every appointment seems to be causing confusion as Lucy feels that the consultants are not all on the same page with one doctor thinking she needs to start chemo and another doctor thinking that it is too early to start treatment. While Lucy now seems to be utilising the support offered by the clinical team, she has continued to feel uncertainty and experience anxiety in the second interview. This would suggest that the support offered by the clinicians has not helped to reduce Lucy's feelings of anxiety, perhaps due to the uncertainty caused by seeing too many clinicians.

For a number of participants there was a change in their perceived level of formal support, with participants initially feeling unhappy with support from hospitals and clinical staff. However, six months later they are now happier with the level of support they had

received, which interestingly seemed to coincide with receiving fewer follow up appointments:

*Rachel Int 1 – “When I first got diagnosed it was like erm it’s just going to be routine now cause it’s not that bad, then when we went to see the consultant they says oh well no you’re going to have to have everything taken away. Then it was like well now we think it might have spread you know and then, we don’t know whether it is and it, it was like every time I went to see this consultant he was like the grim reaper”*

*Rob Int 1 – “Which I was just, completely flattened us yeah and what you’re looking for really is support, and I just didn’t seem to be getting any... I would of liked some counselling in, in the first few weeks, I could of done with that, I did go to the GP and ask him if I could have some cause I was feeling, wasn’t feeling right mentally, and he, he looked at me notes and said ‘Dr Bromley’ thinks you’re alright’ don’t think you need any”*

In their first interviews both Rob and Rachel were unhappy with some aspect of their supportive care. For Rachel this stemmed from a constantly changing diagnosis. When she says that every time she went to the consultant he was like the grim reaper, this would indicate that she felt that the news was getting worse every time she saw him. This perhaps linked into fears of uncertain future discussed earlier, as every time she saw the consultant her prognosis had changed and this may leave her not knowing what to expect. Furthermore, by calling the consultant the ‘grim reaper’, this may tie into thoughts of death and dying and could suggest that at the time she was not confident about surviving.

On the other hand, Rob felt that he was not getting the kind of support that he needed, as he had started to have feelings of anxiety after his diagnosis which got to the stage where he felt he needed to talk to someone about it. However, despite asking his GP to talk to someone about it, he was told that his consultant did not feel that he needed to talk to anyone and so he was left to deal with it on his own. He describes feeling like he was not receiving any formal support; however he would still have been attending scheduled clinical appointments after his diagnosis and it is perhaps because he was not receiving the kind of support that he would have expected, or wanted, that led to these feelings of being

left on his own. This feeling that the doctors are not listening to him may also be linked to Rob's diagnosis which was discussed earlier in the interview; Rob felt that the doctors were not listening to his concerns that he may have colorectal cancer, which he has a strong family history of, and had to go to the GP a number of times before they eventually had him screened. This experience may be shaping his attitude towards the clinical support he is receiving as he may have felt that once again they were not listening to his concerns. This raises a question about the different agendas of the clinical team versus the patient which may not always align and if the patient does not receive the supportive care they feel they need then it can leave them feeling disillusioned. Rachel and Rob, like Lucy, discussed feelings of anxiety in their first interview, and it is perhaps the lack of functional support which has contributed to these feelings. This is further highlighted in the example from Rob below, who feels happier with the support he has received from his clinical team and who also felt that his feelings of anxiety were greatly reduced at the second interview.

*Rachel Int 2 – “Think probably because it was the same person that I'd seen, her recognising, you know we that I'd, I'd moved on or I'd not moved on but I'd improved a lot, so since then I haven't had, cause she said would you like to go to every 6 months, which was a real boost for me”*

*Rob Int 2 – “Had to have an MRI scan and they asked if they could repeat the MRI scan after 3 months and the, wh, the scans were all fine, so I'm now on 6 monthly appointments and me next one is at the end of March (pause). (Grant – how did you feel about moving to 6 monthly appointments?) Champion, excellent it's good progress I think... No I think they erm, quite happy now, they know I'm not worried so they're not worried yeah”*

In the second interview Rachel seems to be much happier with the level of support she has received from the clinical team. This seems to stem from being able to see the same consultant all of the time who is noticing that she is recovering well, reinforcing her own feelings about her recovery. This culminated in her being offered six monthly appointments instead of every three months which Rachel saw as confirmation that she was recovering well. This improvement in the functional support which Rachel has received



from the clinical team appears to have helped with her feelings of uncertainty that she expressed in the first interview. At the time of the first interview she felt that her prognosis was worsening every time she went to an appointment. However, by the second interview she felt that she was improving every time she saw her new clinician. Rob has had a similar experience to Rachel. While he was suffering from anxiety in the first interview and felt that he was not receiving support from the clinicians, this seems to have changed by the time of his second interview. Like Rachel, he is happy that his appointments are now every six months instead of three months which he sees as a sign of progress. In Chapter 5.2.7 Rob's feelings of recovery were discussed and how he feels that he is progressing well. The move to six monthly appointments therefore may confirm this belief for Rob. Furthermore, Rob no longer felt that he was suffering from anxiety at the time of the second interview and this reduction in his experience of anxiety may be related to his increased satisfaction with the support from clinical staff and their reinforcement of his belief that his recovery from cancer is progressing well.

The results above highlight that the use of support services provided by hospitals has the potential to reduce feelings of anxiety and uncertainty about the future for patients. However, similar to the findings of Bloom et al, (2001) who found that support reduced distress only if it was emotional and instrumental, the above results highlight that support is only effective at reducing anxiety and uncertainty when the participant feels that the support provided is adequate. For example, while Lucy felt that she had more contact with clinicians in the second interview, seeing different doctors every time she went to the hospital added to her uncertainty rather than reduced it. On the other hand, Rob and Rachel felt happier about the amount of support that they received from the hospital staff by the time of the second interview and subsequently experienced less anxiety and uncertainty. Further, John never utilised the support on offer at the hospital by not

reporting his symptoms which may have been indicative of recurrence. Instead, he researched online what may be causing the symptoms and managed to deal with the symptoms by changing his diet. This suggests that, while support can help to reduce feelings of anxiety and uncertainty, if a patient adopts appropriate coping strategies then they perhaps do not need to rely on support mechanisms.

## **6.7 Social support**

While the last sub-theme looked at the use of support provided by the clinical staff, this sub-theme discusses the use of family and friends as a source of support. As discussed by Uchino (2004), support can broadly be defined as the structures of an individual's social life (structural support), and the functions that they serve (functional support) with the latter being better at helping patients to adjust to their cancer. Furthermore, Bloom and Spiegel (1984) found that the size of a patient's social group was predictive of better adjustment to cancer only if they provided the patient with functional support. Some of the participants in this study felt happy with the support provided by their friends and family:

*Geoff Int 1 – “Me wife actually was quite strange erm it was almost as if it never knocked her out of her stride em as if nothing had happened there was quite a few arguments went on at the time however, after the op... during the operation like the day before and then during the operation and then after the operation she was like Florence Nightingale she was amazing so I got the impression that she struggled to cope with it”*

*Geoff Int 2 – “She was marvellous with it and she has gotten over it I don't think she has ever really come round to what it was and what you go through erm she does, it hasn't really affected her, and now she has been a little bit worried recently obviously, and I don't think it's really affected the kids too much... I don't know, they don't, at the time they talked about nothing else but time goes in and you move on you know”*

In the first interview Geoff feels that his main source of support came from his wife, although he feels that she perhaps struggled to come to terms with his diagnosis at first. Geoff discusses that they had quite a few arguments when he was first diagnosed, which he

feels may be because she did not realise how serious his condition was. As discussed earlier, a lack of communication may have led to these arguments as they did not really discuss how they were both were feeling or coping. This is emphasised when he says he ‘got the impression that she struggled to cope with it’ – describing this as ‘get the impression’ suggests that she had not discussed this with him. However, after the operation, her attitude changed and he felt that she was a great source of support, describing her as Florence Nightingale. In the second interview he still believes that his wife is an excellent source of support for him. Furthermore it would seem that she has been his main source of support for him throughout his recent scare as he states that they kept it from the children so as not to worry them. While this may be seen as avoidance, by not telling his children about his recent scare, Geoff is protecting them from what may be unnecessary harm as his symptoms turned out not to be cancer. Harrison, J. et al. (1995) found that male cancer patients tended to confide their main cancer concerns to their spouse only, as Geoff has done, and while at first the support he received from his wife was perhaps not emotional, she became more supportive as time went on, and it was she who eventually convinced him to report the symptoms which has caused him to suspect that his cancer had recurred. The reporting of his symptoms reduced the potential impact of his future disorientation as he had considered cancelling his holiday due to concerns about recurrence. However, by reporting his symptoms and being told the cancer had not returned, Geoff was able to regain a sense of his immediate future.

Some participants, however, felt that they were not receiving enough support from family members, which seemed consistent across the two interviews. This may be because the family members do not want to talk about cancer, or because the patient does not want to worry them by sharing their concerns:

*Rachel Int 1 – “Me parents you know they, they’ve always been very supportive you know, but without worrying them you know I wouldn’t really discuss things with them, and me husband really, erm, he I mean obviously looked after me being at every appointment and everything but, you don’t really, I don’t really talk through, like, through things with him cause he’s one of those like, that keep it to he doesn’t, doesn’t like talking about things”*

*Rachel Int 2 – “they’re not, they’re not that sensitive about it (laughs... I mean I did have a conversation with one of them once, and one of (husbands) side of the family, they, we were there for, a few weeks ago er, em and we spent actually it was new, I was going to say it was a few weeks ago, it was new year, there has been a new baby, like they live in Wolverhampton, we went down there and they were very understanding”*

In the first interview Rachel insinuates that she does not necessarily communicate her concerns to her parents as she does not want to worry them. Rachel also feels that she cannot talk to her husband about things as he is the type of person that keeps difficult thoughts to himself rather than talk them through. However, this lack of communication may be related to her primary concern around not being able to have children. As discussed earlier she feels that her husband may partially blame himself for not being able to give her children and this may be why she avoids talking to him about her concerns. Furthermore, she also stated elsewhere in the interview that she did not like discussing not being able to have children with her parents as it upset them because they knew there was nothing they could do to help. A reluctance to discuss this with her family may lead to her holding other things back as well and may lead to feelings of not having social support. In the second interview these feelings have continued, and she still feels that she has to keep certain things from her husband and from her parents. Rachel feels that her husband’s family are more supportive than her own family, who she feels are quite insensitive about her inability to have children. When she discussed her feelings about not being able to have children with members of her husband’s family she felt that they were much more understanding. Rachel appears to adopt a similar attitude about protecting her family from distress as Geoff. However, where Geoff still had his wife to confide in, this does not appear to be the case for Rachel with her husband. Linking back to the discussion in the

literature review around the confiding of main concerns, (Harrison, J. et al. 1995) it is evident that Rachel feels that she cannot confide her main concern about infertility in either her husband or her parents. Over the course of the two interviews Rachel has continued to feel a sense of future disorientation as she struggles to adapt to a life without children. A lack of functional support from her close family and an avoidance of communicating her concerns may be contributing to her disrupted view of the future and impacting on her life.

Like Rachel, Lucy felt that the support that she received was not as good as it could have been; however for Lucy this is exacerbated by the fact that having had cancer previously, she feels that her family were more supportive the first time:

*Lucy Int 1 – “I needed a bit more than that a bit of a cuddle, a kiss you know, to feel safe. Andrew being the same as well I don’t know em, he’s not really spoken a great deal to me about how he’s felt em, I mean the last time he was saying things like ‘I don’t want to lose you’ and all of this, this time he’s saying you know ‘It’ll be alright’”*

*Lucy Int 2 – “But, but Andrew is there and I can get a cuddle off of him if I want one, he doesn’t say anything, he doesn’t ask anything erm, he just when I was diagnosed again at the clinic, all he said was you’re strong, you’ll come through it”*

The above quotes demonstrate that Lucy has encountered a similar experience to Rachel in that while she knows that the support is there from her partner if she needs it, it is perhaps not as forthcoming as it could be, or was in the past. In both the first and second interview she feels she has to ask for her partner to cuddle her if she needs one, describing in the first interview that she needs that to feel safe, and in the second interview she again hints that she has to ask him for a cuddle when she needs one. There is also a sense in this quote that Lucy feels that the support he gave her when she was diagnosed with breast cancer is not the same now that she has ovarian cancer, as she highlights a change in the way he spoke to her about cancer. Furthermore, in both quotes, there is a lack of communication about cancer, something which was discussed in relation to a number of participants in the

previous chapter. In both quotes Lucy mentions that Andrew does not talk to her about cancer anymore, something which he apparently was more active in doing when she had breast cancer. This lack of communication may be contributing to Lucy's feelings that the support she receives from her partner is not as good as it could have been, if she was used to him being more open when she had cancer the first time. Like Lucy's feelings towards support from her McMillan nurse, she states that the support from her partner is there if she needs it but she is reluctant to ask for support, perhaps feeling that she should not have to ask. Like Rachel, Lucy has still not adapted to the disrupted view of her future, and while this may be exacerbated by the onset of a new tumour, the lack of functional support may be contributing to her experience of future disorientation.

The following quotes demonstrate that John also felt that he had to hide how he felt from his parents, but at the second interview his attitude has changed to some extent and he is happy sharing things with them:

*John Int 1 – “Yeah I mean my wife's brilliant she's been me nurse, me best friend and everything basically over the last few months, erm me family's always been there... didn't want to upset my mam and dad too much cause they've got enough on their plate being 70 year old and looking after me sister”*

*John Int 2 – “I'm open as anything with them, I just they know everything I have been through, they know I am fine, if I had any problems with them I would tell them straight away now”*

In the first quote above, like Geoff, John's main source of social support comes from his wife, whom he describes as being his nurse and his best friend. This would suggest that she has helped to look after him during his recovery and also that she has been the person that he would confide in if he had any concerns. This is further emphasised when he hints that he did not tell his parents everything that he was going through, saying that he did not want to upset them. While Geoff wanted to protect his children from unnecessary worry, John wants to protect his parents whom he feels have enough to worry about without him

adding to it. The quote from the second interview highlights that John now feels more comfortable talking to his parents about his cancer and recovery as he says 'I would tell them straight away now' thus emphasising that in the past he would hesitate to tell them anything. Furthermore, when John says 'they know I am fine' this further evidences John's belief highlighted in the recovery sub-theme that he is recovering well from his cancer. Like Geoff, John has experienced a reduction in his experience of future disorientation over the course of his cancer journey relating to his occupational concerns, and has continued to draw on his wife as a source of functional support. Therefore, by having his wife there to support him and listen to his concerns, this may have allowed him to come to the decision to irrigate his stoma rather than wear a bag which has allowed him to accept his new future and continue working in the catering industry.

The results presented here suggest that, for the most part, a patient's satisfaction with the level of social support they receive from family members has remained stable. Interestingly for those patients who are unhappy with the level of support they received from their family, they tended to get some form of support from their in laws rather than direct family members, and these participants are also the same ones who discussed a lack of communication with their family in the impact on family life sub-theme. This suggests that an increase in communication with their immediate family could lead to an increase in their satisfaction with social support. This is further evidenced by John who felt like he had to hide things from his parents in the first interview to protect them but now feels more confident about his recovery and has started to share more with them, thus increasing his levels of support. As discussed by Harrison, J. et al (1995), a large number of cancer patients had no one to confide in when it came to discussing their main cancer concerns, which may explain why patients are unsatisfied with their level of social support. However, when a patient has at least one main confidante in whom they can share their

main concerns, then this may lead to better adjustment to cancer. The experience of the patients discussed above seems to support these findings as John's recovery from cancer seems to be progressing well with a reduction in his experience of future disorientation, occupational concerns and fear of recurrence over the course of his cancer journey. Geoff also has experienced a reduction in his fear of recurrence due directly to his wife making him report his symptoms to his CNS. Rachel and Lucy on the other hand feel that they are unable to confide in their immediate family members and have both experienced a continued sense of future disorientation and have both expressed continued feelings of anxiety over the course of their cancer journeys.

## **6.8 Summary**

The results presented in this chapter show that there are various coping strategies employed by participants in response to a diagnosis of cancer, and the utilization of these coping strategies continues long after patients have finished treatment. Patients use coping strategies for a number of different reasons, such as moving on from their cancer, avoiding situations which may remind them about the consequences of their cancer, suppressing their emotions, or keeping things from family members to protect them from distress. The majority of the coping strategies discussed above seem to remain stable over time, which suggests that once a participant has adopted certain coping strategies, positive or negative, they may continue to use them over time which may not be the best way of adapting to living with and beyond cancer. Evidence from the literature review suggested that the use of negative coping strategies (such as avoidance) can lead to more anxiety and this seems to be evident from the examples presented in this chapter. The use of positive coping strategies, such as problem focussed coping and acceptance, seem to be better suited to allowing patients to come to terms with their new future after a cancer diagnosis and can help to prevent or reduce the impact of future disorientation.



The results outlined in this chapter highlight that the use of effective coping strategies may moderate the impact of future disorientation. Those participants who employed problem focussed coping strategies, such as John in relation to the occupational impact of his stoma, seemed to adjust better to the disrupted view of their future. However, those participants who used coping strategies such as avoidance, like Lucy and Rachel, seemed to continue to experience a disrupted view of their future which had a number of consequences in relation to feeling comfortable making plans, occupational concerns and concerns around infertility. Furthermore, those patients who felt that they could draw on functional support either clinically or from family members also seem to have experienced a reduction in their experience of future disorientation in terms of occupational concerns. When a participant felt that they had no functional support, (as defined in Chapter 2.7 as the explicit functions that a support network serves such as the provision of services, advice, or emotional support) to draw on then this coincided with either a continued sense of future disorientation or the emergence of these feelings in the second interview.

## **Chapter 7 – Future Disorientation**

The previous two chapters explored potential causes of future disorientation in adults living with and beyond cancer and factors which may protect against it or reduce its impact. The present chapter explores consequences of future disorientation if patients are unable to adapt to disrupted views of their future. Future disorientation was defined in Chapter 2 as a response to the disorder that emerges out of a cancer diagnosis and a realisation that people who have had a cancer diagnosis are living with an uncertain future. Patients can be left with a feeling that their lives have been disrupted because of their illness and future disorientation may occur when patients fail to adapt to the changes that have taken place because of their illness (Roberts & Clarke, C. L., 2009). While the literature review identified that future disorientation may lead to concerns about infertility, and concerns regarding future employment which were discussed in Chapter 5.2, a number of other potential consequences of future disorientation emerged from the interviews. Three sub-themes are discussed within the future disorientation theme: ability to plan for the future, feelings of recovery, and life on hold.

### **7.1 Future Plans**

As discussed in Chapter 2, cancer patients can be left with a feeling that they are living with an uncertain future. One of the consequences of this is that it can lead to patients feeling uneasy about making plans for the future in case they are too ill to fulfil them. However, this sense of being able to plan for the future was not consistently expressed by all participants over the course of the two interviews. The quotes below highlight that certain events can cause these feelings to emerge in participants who had previously felt comfortable making plans:

*Lucy – Int 1 “Well I’ve had to, I think you can’t not. I did for a while think well why am I going to bother... say I felt as though I was running along life rather than being part of it, I now feel that I’m in life again and I’m part of it*

*and in a way what will be will be. So my flight's booked, my hotel's booked (America trip)... 6 months is a long time in this life and who knows but I can't just sit around waiting"*

*Lucy Int 2 - "Erm the idea of going off away on a holiday or anything like that, I would be too worried I took ill when I was away, you know, not that, I've got any indication that I am going to take ill, you know it's just this, this driving force or belief that I seem to have at the minute you know, that that's it, and it's hard to shift"*

The quotes above show that the impact cancer can have on patients' ability to plan for the future can change over time depending on circumstances. In Lucy's first interview she appears to be quite happy making plans, with a trip to America with her dancing group to look forward too. While she discusses in this interview the need to make plans as she feels that you cannot just sit around waiting for things to happen, she does admit that there were times in the past when she did not like making plans as she did not see the point. The fluctuating nature of future disorientation for Lucy is further evidenced by the quote from her second interview where she is now in a place where she does not want to make future plans again. The discovery of a new tumour seems to have impacted on Lucy's views of the future and led to this change in her ability to make plans, as is evidenced when she says she would be too worried she took ill when she was away. This feeling of waiting to be ill represents a distinct change in her attitude to future planning from the first interview. Lucy's fear of progression of cancer was discussed in Chapter 5 and is evidenced again in the second quote in relation to her ability to make future plans. She states that even though she has had no indication from her consultants that her condition is going to deteriorate she has a strong belief in herself that she is going to be ill. This could be related to her fear that the medication she is taking to halt the growth of the tumour will not work and she will have to undergo chemotherapy again. As discussed in Chapter 5, Lucy encountered numerous other consequences of her cancer diagnosis such as feeling a loss of control, anxiety, and recurrent intrusive thoughts related to her cancer. All of these factors may be impacting on her ability to make plans for the future as feeling that she had no control over

her cancer seemed to add to her sense of uncertainty over her future. This prevented her from planning a holiday with friends as she was unsure how well she would be and did not want to ruin anyone else's trip.

Furthermore, Lucy expressed feelings of anxiety in the second interview which seemed to coincide with a reduction in her ability to make future plans. However, while it is possible that anxiety or a loss of control is contributing to the experience of future disorientation they may also be consequences of her recurrent cancer. Coping strategies and sources of support were discussed in Chapter 6 as factors which could reduce the impact of future disorientation. As Lucy has experienced a reduction in her ability to look ahead and plan for her future this would suggest that she is not using effective coping strategies. The use of avoidance as a coping mechanism and emotional suppression were identified in the literature as contributing to anxiety and linked to poorer outcomes (Llewellyn, McGurk & Weinman, 2007) and this certainly seems to be the case with Lucy. Therefore if anxiety is associated with an inability to plan for the future then this would highlight that Lucy's coping strategies are not helping her to adjust to her disrupted view of the future.

The following quotes further emphasise that whether or not a participant feels comfortable making plans for their future may change over time depending on certain factors:

*Geoff Int 1 - "Erm, I haven't let it affect us at all about making plans... when me mother died erm I eh... I inherited her a... ah flat erm and the ideas was to sell it but it ... it hasn't gone so we've decided to keep it and to let it. Erm, and then th... th... this is why I'm saying this is actually going to sum it up for you is because the plan is that you know 10 to 15 years' time (to sell it)"*

*Geoff Int 2 - "Certainly never, ever really thought well I'm not going to book a holiday next year just in case you know I wouldn't do anything like that I mean you can't really live that way. If it happens it happens and you alter your plans, ironically the holiday I just had we booked before I had the symptoms and the colonoscopy was em five and a half weeks before we went away, it was actually mentioned if it was cancer, would I be able to go"*

In the first interview Geoff does not seem to have any issues looking ahead and planning for his future as he states that he plans to sell the house he inherited from his mother in 10-15 years' time. This would suggest that Geoff feels confident in his recovery enough that he expects to be around in 10-15 years when he plans on selling his mother's house. It is interesting to note that Geoff is able to look so far ahead considering his fear of death which was discussed in Chapter 5. Given that his fear of death was linked to a specific traumatic experience however, it may not be long term and therefore not impacting on his ability to plan for his future. At the time of the second interview Geoff had experienced symptoms in his body which were similar to those encountered when he was first diagnosed, this also coincided with a holiday which he had planned and he had to consider the possibility that he would have to put these plans on hold. This again suggests that the impact cancer can have on a patient's ability to plan for the future can change depending on a patient's circumstances as while Geoff normally feels okay planning ahead, the experience of these sensations had caused him to consider postponing his holiday in case he would have to undergo treatment. Geoff's experience therefore would highlight that the experience of fear of recurrence may have a direct impact on how a patient views their future. While Geoff had no experience of fear of recurrence in his first interview, the onset of symptoms before his second interview led him to believe that his cancer may be returning and he therefore adjusted his view of the short term future as his recovery from any subsequent recurrence would be a priority. While Geoff has experienced future disorientation, it only appears to be short term and linked to the one instance when he suffered a recurrence of symptoms. This would suggest that having his symptoms checked and being told the cancer had not returned has alleviated his future disorientation and he has been able to return to his previously held view of his future. However, had he not had his symptoms checked then his future disorientation may have continued longer term. This reinforces the idea discussed in the previous chapter that positive coping strategies can help

to reduce the impact of future disorientation as Geoff returned to his previous state where he can look ahead and plan for the future which is evidenced when he discusses never wanting to not make plans just in case. Like Lucy, Geoff has encountered a number of consequences of his cancer diagnosis and treatment such as occupational concerns, fear of recurrence, and fatigue. And while he also experienced future disorientation in terms of concerns about making future plans, this only seems to have been a temporary response to fear of recurrence. Geoff appears to have adopted a problem focussed coping style to deal with his fears by having his symptoms checked which allowed him to reclaim his ability to look to his future. With Relation to Lucy's experience this would suggest that while fear of recurrence may only temporarily cause a disruption to views of the future, when those fears are realised and the cancer comes back, positive coping strategies alone will not reduce its impact. While Lucy did tend to use avoidance and emotional suppression as her coping mechanisms, this was not the case with any sign of symptoms of cancer which she was proactive in reporting to doctors. Therefore it would appear that Lucy's inability to make plans for the future is directly caused by her recurrent cancer.

While the participants above initially felt comfortable making plans for their future, the onset of a specific event such as recurrent symptoms, or the discovery of a new tumour, led to a change in their ability to do this. Being comfortable looking ahead and making plans may therefore be something which fluctuates over time. The quotes below highlight that the ability to make plans can also re-emerge as a patient continues along their cancer journey:

*John Int 1 – “They had said obviously the travel insurance would go up and stuff for us going away on holiday and I’ve been in touch with them and they’ve said it covers everything apart from cancer anyway so I’m just waiting to see what happens with that and hoping to have a holiday like later in the year if everything goes to plan sort of thing”*

*John Int 2 – “Said after last year we would make this year ‘us year’ sort of thing, do what we want, when we want and just go for it, holiday when we want, and feel like we don’t hold back... and that’s pretty much the way we have started by going to Tenerife last year, last week even”*

The quotes provided by John above suggest that even when a patient feels that they are comfortable looking ahead and making plans for their future, there may be certain factors which cause them to re-evaluate this. In John’s case he has had to think about the impact that a cancer diagnosis will have on his holiday insurance, and he has been restricted in his ability to make plans while he waits to see if his bank will continue to cover him and his wife. This highlights that even when a patient is comfortable looking ahead and making plans for their future, some aspects of having had cancer can still have a negative impact on patients in this regard. In Chapter 5 it was discussed that cancer had led to John considering a career change as he did not want to wear a stoma while working in catering. Therefore it would appear that John has experienced future disorientation in more than one aspect of his life as in addition to his occupational concerns he seems to have some issues around making long term plans in relation to holidays. When asked if he had made any plans for the future, he did not offer any specific examples. Therefore it is possible that the uncertainty relating to his employment in the future may have been a factor in his ability to make plans, such as holidays due to a potential change in his financial situation, possibly compounded by a raise in the price of holiday insurance.

By the time of the second interview, however, John had resumed making plans such as trips abroad with his wife. Although he stated in the first interview that he was happy making plans, he seems to contradict this in the second quote, in which he states that his wife and he ‘feel like we don’t hold back’ this year and have holidays when they want. This would suggest that in the past they had been holding back and that they have only begun to feel comfortable looking ahead and making plans. In the first interview John was still coming to terms with having a permanent stoma following his surgery, something

which he seems to have adapted to since commencing irrigating his stoma rather than wearing a colostomy bag. Secondly, he had concerns about his future employment, not knowing if he was going to be made redundant, or whether he wanted to continue working in the catering industry. This was resolved when he moved to a new catering job and started irrigating before work and he perhaps feels more financially secure now. Finally, at the time of the first interview John was still experiencing a lot of pain in his buttocks and lower back which meant he could not sit down for long periods of time. This would have made travelling for any distance difficult however, at the time of the second interview this was no longer an issue. The experience of John in particular points to a number of potential causes of future disorientation such as occupational concerns and the impact of functional impairment. This supports the inclusion of multiple causes of future disorientation into the theoretical framework.

The following quotes highlight that other factors may impact on a patient's ability to look ahead and plan for their future. The uncertainty around upcoming clinical appointments can result in patient's delaying the making of any plans:

*Sarah Int 1 – “Well I made plans for April, so that's probably about as far as I'll go (laughs) and erm (pause) yeah going to see Harry Potter, the Harry Potter thing it's ah eh, just a two day thing but I was hoping to take erm (grandchildren) when I got the news from CNS-C”*

*Sarah Int 2 – “Nut, I'm just probably about the same... No, what I said was cause I've only taken aw... I've only been away with the children twice this year. I said if it's alright after me colonoscopy... then I'll book another trip away for us”*

In the above quotes Sarah seems to be wary about looking ahead and planning for her future; although in both interviews she discusses plans that she had made months in advance. On both occasions she discusses her plans in relation to getting good news from her follow up appointments. Sarah had planned a trip to Harry Potter World, a museum dedicated to the popular film franchise, with her grandchildren. This trip was scheduled



for approximately four months after the date of the first interview as she felt that was the farthest into the future that she would be comfortable making plans. What is interesting to note in this quote is that Sarah planned the trip after having a follow up appointment with her CNS. While she did not openly discuss concerns about cancer recurrence in the first interview, this quote would suggest that perhaps she has some concerns around recurrence. The fact that she seems unwilling to make definite plans before she has had a follow up appointment would suggest that she is concerned that the results may be negative and she would need to cancel or alter her plans. In the second interview Sarah feels that she is still uncomfortable making plans too far in advance, describing it as being about the same. This highlights that for Sarah, these feelings may be long term which is in contrast to the experiences of Geoff and Lucy. However, in both cases with Sarah, she seems to plan trips and holidays around her clinical appointments and does not make definite plans until she has been told her scans are clear. Therefore, it may be that like Geoff and Lucy, how comfortable she feels making plans is not stable and is influenced by factors such as fear of recurrence.

Like Sarah, Lindsay also did not feel comfortable making plans for her future at either the first or the second interview, expressing in both interviews that she did not like making plans any more than a few weeks in advance:

*Lindsay Int 1 - "But erm, now I... I don't plan for the future anymore (pause). Again I think that's got a lot to do with age as well not now, no er, just take every day as it comes. I may plan a few month ahead"*

*Lindsay Int 2 - "Two, three weeks... yeah no longer than that no, (Grant - so when you do go on holiday and things is it just a spur of the moment, you just decide you are going to go away?) Yes ahuh"*

The above quote demonstrates that Lindsay, like Sarah feels uncomfortable making plans for her future and this has continued through both interviews. In the first quote there is a degree of contradiction in what Lindsay says. While she states first of all that she does not

plan for the future anymore, instead she now takes one day at a time suggesting a complete suspension of making any plans, short or long term. However, later in the interview she discusses that she may plan a few months ahead indicating that she sometimes feels comfortable making short term plans. However, like John and Rob, when asked to discuss any specific plans she had made, she was unable to give any specific examples. In Chapter 5.2.7, Lindsay discussed the experience of pain and discomfort since her operation, and therefore like John, Lindsay's reluctance to make long term plans may be impacted upon by functional impairment. At the time of the second interview Lindsay described continued experience of pain and discomfort which may explain why she still feels uncomfortable making future plans. Contrastingly, John had resumed being able to make plans by the time of the second interview which seemed to coincide with a reduction in his experience of pain. This suggests that Lindsay's on-going pain may have been a factor in her failure to adjust to a new future and contributed to the negative outcomes of future disorientation. The above examples from Sarah and Lindsay reinforce the idea that a number of factors may lead to an inability to make plans for the future, such as functional impairment and fear of recurrence related to upcoming hospital appointments.

Unlike Geoff, Lucy and Sarah, who expressed concerns around making plans for their future in at least one of the interviews, this was not the case for all of the participants, as evidenced in the quotes below:

*Rachel – Int 1 “I’ve never, like, not thought oh well I’ll not be here or you know like let’s not make plan, I’m one of these oh let’s book a holiday a year in advance, let’s book so you know yeah, I like, I’m definitely like look ahead... about a year ago, didn’t want to go on holiday, didn’t want to go away or anything, but then, now it’s like yeah just, just get the holidays booked”*

*Rachel Int 2 – “Yeah we’ve booked for next February actually (G – yeah), we’re going away in eh, in May with the family and we thought it would be a bit traumatising for me husband, being for a fortnight with my family (laughs) but I mean normally we go away with me mam and dad and that’s fine the four*

*of us get on... So I said to Richard well why don't we book a holiday, just for the two of us to look forward to, so we've booked to go to Barbados"*

*Paul Int 1 – "Oh yes, yeah I still make plans in advance oh aye. Oh yes I've made plans in advance alright... Aye well I'm looking fo... looking for a holiday for next month for me and the wife it's our wedding anniversary and me 65<sup>th</sup> birthday so I said I'm gona have a week away at least."*

The first quote above provided by Rachel demonstrates that she has maintained a sense of being able to plan for her future over the course of the two interviews. In the first interview while not discussing any particular plans, she does discuss that she has always been the type of person to look ahead and make plans such as booking a holiday a year in advance. This sense of being able to plan for the future seems to have continued over the 6 months between the two interviews as Rachel again discusses being able to look ahead and this time talks of specific plans she has in terms of holidays with her family and her husband, booked more than a year in advance. However, there is still evidence that despite being in a place where she feels comfortable to look ahead and plan for her future that this can change over time, like with Geoff and Lucy. She discusses in the first interview that there was a time about a year before the interview took place that she did not feel able to plan things. Elsewhere in the interview she also states that around this time she was suffering from anxiety related to finding a lump in her breast. Therefore like Geoff and Lucy it may be that an ability to plan can be influenced by setbacks such as a fear of recurrence or a fear of cancer progression. However, while Rachel does not appear to have any issues planning for her short term future, the impact of her cancer treatment has left her unable to have children. This has caused a disruption to her view of the future as she has been unable to come to terms with her infertility as she had always envisioned children as part of her future. This has caused her to feel distressed and has led to her avoiding situations where she knows young children will be present, such as family parties. She has also expressed feelings of anxiety which have led to occupational concerns as she feels that she is not good enough to effectively carry out her duties anymore. This is another aspect

of her life where future disorientation could impact on her if she feels the need to leave her job or seek alternate employment, the resulting financial insecurity may further disrupt her view of the future.

Paul on the other hand appears to be confident enough to make plans for the future, this is emphasised with his repetition of the word yes when asked if he still made plans for the future. However, while he maintains that he is happy making plans he only discusses that he is looking for a holiday within the next month. The use of the term 'looking for' is interesting here as it suggests that nothing concrete has been planned, and there may be a number of reasons for this. It may be that he and his wife have not found anything suitable, or like John, it could be due to his future employment being in doubt, having expressed concerns that he will not have a job after the summer. Therefore, Paul may have had doubts about booking any holidays due to a potential financial impact of being unemployed. This is similar to the experience of John and further highlights that occupational concerns can lead to a disrupted view of the future.

In light of these results, while it appears that future disorientation can lead to patients being unable to look ahead and plan for their future, there appear to be a number of factors which can influence this relationship. Both Geoff and Lucy have expressed concerns about cancer recurrence, however Geoff only developed his fears after the first interview which also coincided with a disruption to his ability to plan ahead due to uncertainty regarding potential surgery. This would suggest that fear of recurrence was responsible for changes to a patient's ability to plan ahead. However, the experience of Lucy demonstrates that the relationship is perhaps not as straight forward as this. Lucy expressed fear of cancer recurrence in the first interview, but unlike Geoff this did not seem to coincide with an inability to plan ahead, and she felt that she had to make plans. It was not until she suffered an actual recurrence that her ability to plan ahead appeared to suffer. However, as

stated above, there was a point in Lucy's life prior to the first interview where she was not comfortable making plans. This would suggest that while fear of recurrence appears to be a stable construct, as evidenced in the literature (Ghazzali et al, 2012), ability to make future plans is not stable and it may be affected by a combination of factors not just fear of recurrence alone.

The results presented above and in earlier chapters have shown that fear of cancer recurrence is a potential cause of future disorientation in relation to making future plans. Several other consequences associated with living with and beyond cancer have also emerged as having an effect on planning for the future. For example the experience of pain and discomfort as a consequence of cancer treatment can have an impact on whether or not a patient feels comfortable making any long term plans. This was evidenced by the experience of Lindsay, who prior to her surgery enjoyed going caravanning holidays with her husband. Since her treatment she no longer feels comfortable making long journeys and tends to plan trips at short notice depending on how she is feeling at the time. As discussed earlier in this thesis (Chapter 5.2.6), the experience of functional impairment can lead to the experience of future disorientation in terms of employment. This in turn may have an indirect impact on whether or not a patient feels comfortable making plans for the future as the financial uncertainty related to feeling that you cannot return to work may make it difficult to make any long-term plans.

## **7.2 Feelings of not recovering well from cancer**

The theme of recovery was discussed in the interviews and explored patients' sense of how they felt they were progressing in their lives after cancer treatment. Like other themes discussed above there were some patients whose sense of recovery had changed somewhat in the time between the interviews whilst for others there was no change. The quote below from Lindsay highlights how her sense of recovery has altered in the intervening times

between the interviews. In the first interview she was very emotional and was concerned about her physical condition however, by the time of the second interview she seemed to be happier with how she was progressing:

*Lindsay Int 1 - "Especially the stairs, every time I walk up I keep saying oh I'll have to get a stair lift, cause it's getting harder. If I go up more than once a day then I could cry. Because I really struggle by the time I get to the top. I have applied for a council bungalow, but could take years to get one"*

*Lindsay Int 2 - "Erm I lost quite a lot of lung when they took the tumour so, erm if I keep going the way I am then I'll be happy (Grant - yeah), obviously I think the breathing will get better the more weight I can take off (Grant - mhmm), then the lung won't be struggling as much (Grant - yeah), as it has been, so yeah everything is looking pretty good"*

The above quotes show a marked shift in the type of language used by Lindsay between the two interviews, "happy", "better", "good" are all positive words which suggest that she is feeling better about her condition which is in stark contrast to the previous interview where the words she used to describe her recovery were all negative "couldn't", "cry", "struggle". Therefore, there may be a relationship between physical condition and a feeling of recovery. In the first interview Lindsay was concerned about her weight, whereas in the second interview she talks about her breathing improving with the more weight she can get off suggesting that she feels she has lost weight in between the two interviews. This is very similar to the results presented in Chapter 5.1.1 where a number of the participants seemed to associate their physical fitness with their cancer and in particular seemed to feel at less risk of recurrence if they felt physically fitter. This may also relate to the idea of functional impairment discussed in the previous sub-theme which may contribute to feelings of future disorientation. A sense of recovery therefore may constitute that functional impairment is having less of an impact. As discussed in the previous sub-theme, on-going physical problems after her surgery has had an impact on Lindsay's ability to make plans for the future when it came to arranging holidays with her husband. This improvement in her recovery seems to be associated with another aspect of future

disorientation, the ability to make future plans which was discussed in the previous sub-theme. Initially Lindsay commented that she never planned anything in advance and took each day at a time. By the time of the second interview her view had changed to planning things two or three weeks in advance. While this may seem like a small difference, it suggests that Lindsay is progressing well and is feeling more and more comfortable making plans in advance as time goes by. Furthermore, in reference to religious coping which was outlined in Chapter 6.4, Lindsay has continued to adopt a deference style of coping which according to Thune-Boyle et al. (2006) can result in better adjustment to illness. This would suggest that the use of an effective coping strategy may be aiding her sense of recovery which in turn has left her more comfortable to make plans for her future.

The below quotes show that Rob had a similar experience to Lindsay in that he felt that his recovery was improving over time, and he also seemed to associate his recovery with a sense of physical well-being:

*Rob Int 1 – “No not really, didn’t make any difference, I mean after the surgery I had to stay in the house for 6 weeks and not do anything until everything healed up I mean walking, 5 minute walk to the paper shop to get a paper, I was absolutely wrecked by the time I got home”*

*Rob Int 2 – “Yeah, exactly, yeah, feel fitter, stronger, healthier, better, just feel like I’m making, going in the right direction”*

Rob seems to associate his recovery with feeling physically fit, as at first he felt that he could not really leave the house while he was recovering from surgery as any sort of physical exertion left him feeling “wrecked”. However, as discussed earlier in this thesis he has resumed physical exercise in terms of going swimming and has also joined a support group to help lose weight. All of this has left him feeling physically fitter than he was before and the language used in the second quote shows that he feels like his recovery is moving in the right direction. He uses a lot of positive adjectives to describe his physical well-being in the second interview, “fitter, stronger, healthier, better”, which is in contrast

to the first interview when he talks negatively about his physical condition “do nothing”, “absolutely wrecked”. This highlights a marked improvement in how Rob feels he is recovering from cancer. Rob seems to place a lot of emphasis on physical fitness, feeling that being physically fitter would reduce the risk of recurrence. Also discussed earlier was Rob’s feeling that he was somehow responsible for developing his cancer, which seemed to stem from being told that his cancer was not caused by genetics. If Rob feels that he was responsible for his cancer, and that being physically fit will reduce his risk of recurrence, then it stands to reason that feeling physically fitter would also lead to an increase in his sense of recovery. Rob’s experience further highlights that functional impairment can lead to future disorientation as before he began having feelings of recovery, any sort of physical activity left him feeling tired and would restrict his ability to plan any sort of activity that could result in exhaustion. Rob also discussed recurrent thoughts related to cancer, often thinking about how bad things could have been, or still could get. At the time of the second interview Rob seemed to have a reduction in recurrent thoughts about cancer which may also be linked to his continued sense of recovery. As he feels physically fitter and that he is progressing well, this may lead to a reduction in recurrent thoughts about cancer which seemed to be related to the possibility of his cancer recurring.

For others there can be a continued sense of recovery over time, where they may have felt that they were recovering well at the first interview and this has continued:

*John Int 1 – “Pretty much, pretty much I would say maybe 90% (back to normal), yeah like I say it’s not, it’s maybe only been what five weeks since the operation I think it is, five maybes six weeks maximum it is and I think obviously I’ve still got a little few aches and pains”*

*John Int 2 - “Absolutely brilliant, they are just chuffed to bits, like that I’ve, I’ve made a full recovery so far an everything so they’re just brilliant about it... I feel more confident about it, in meself and stuff like that as well, I mean if I’m feeling down or bad about anything then I think that they need to know about it as well then they can see why I am feeling down sort of thing, so yeah but I mean I haven’t felt down at all so”*



Like Lindsay, there is a shift in the type of language John uses when talking about his recovery. Although the shift is not quite as marked as with Lindsay, it still suggests that he feels he has improved. In the first interview John states that he feels he is pretty much back to normal. He then goes on to describe experiencing aches and pains in relation to his operation which would suggest that the pains he was experiencing at this time were preventing him from feeling like he was fully back to normal. Comparing this to the language he uses in the second interview, John appears to be much happier with his recovery. He describes his recovery as “absolutely brilliant” and says that his parents are “chuffed to bits that he has made a full recovery”. This suggests that John is now in a place where he feels that he is back to where he was before he was diagnosed with cancer. Furthermore, this feeling of having made a full recovery has led to a change in John’s attitude when it comes to discussing his recovery and any issues with his parents. In the first interview he felt he had to keep things from them as he did not want to worry them, “I don’t, didn’t want to upset my mam and dad too much cause they’ve got enough on their plate being 70 year old.” In the second interview however he feels he has made a full recovery, this has led to him feeling more confident about discussing things with his parents and has now told them everything that he had held back from them before. However, it is interesting to note that John says he has made “a full recovery so far” this would suggest that he does not believe that he is 100% through his cancer journey. This may be related to his uncertainty about cancer recurrence which was discussed in Chapter 5. In the second interview John mentioned that there has been two occasions lately where he felt that he was experiencing new symptoms of cancer. In the previous sub-theme the link between John’s functional impairment and future disorientation was discussed and this is evidenced again in the above quotes. By the time of the second interview John had begun to regain a sense of his future which coincided with a reduction in functional impairment related to aches and pains and his stoma. The reduction in his functional

impairment and experience of future disorientation may then have contributed to his sense of recovery.

However, while the above participants all felt that their physical recovery from cancer was improving over time this was not the case for all of the participants. The quotes below demonstrate that Geoff continued to feel a lack of stamina since his operation:

*Geoff Int 1 – “Erm, the one thing that I’ve noticed is, th... that I never got back was the stamina or strength that I had, I don’t know why that is, I mean I was told at th... th... the time before the operation that I would never really be the same again erm an... and always be... before probably me fittest was actually when I had the tumour which sounds stupid”*

*Geoff Int 2 – “Oh yeah, I remember walking around the supermarket and by the time I get to the end I’m, the legs are aching, I’m knackered basically, and I’ve been, I’ve generally been like that since I was ill and whether or not I am worse recently I don’t know, but when you’ve sort of got doubts about it you tend to sway that way”*

Like Rob, Geoff feels that his physical fitness has suffered after his operation, but unlike Rob there has been no improvement for him over the course of the two interviews. In the first interview Geoff talked about the loss of stamina he had faced since his operation, and in the second interview this continued to be the case. Like Rob there seems to be a connection between a sense of recovery, physical fitness and fear of recurrence. Whereas Rob felt that he was getting fitter and recovering better, and his experience of fear of recurrence seemed to lessen, this was not the case for Geoff. While Geoff tried to regain fitness by going to the gym, he did not feel it was making any difference and his experience of fear of recurrence worsened over the course of the two interviews. Similarly to Rob he seems to be relating fear of recurrence to his physical fitness, as while he says that his stamina has never returned since his operation, he appears to be more aware of it as an issue now since experiencing symptoms. Furthermore, Geoff’s only expression of future disorientation stemmed from his experience of symptoms and the fear that his cancer had returned. As discussed in Chapter 5.2.7, Geoff has continued to experience aches and

pains in relation to his cancer and this would further suggest that a sense of recovery may help in adjusting to a new view of the future. Geoff's continued feeling that he is not recovering may be associated with his experience of negative outcomes related to his future disorientation. He has experienced a number of symptoms since his treatment for cancer, including diarrhoea which has caused him problems while working as a delivery driver. Like John however, he managed to find a solution which has allowed him to continue working in the same job. The experience of Geoff again serves to highlight the impact that future disorientation can have on the working lives of people living with and beyond cancer. His ongoing functional impairment relating to his treatment for cancer can lead to feelings that he is not recovering from cancer. Had Geoff not been able to take medication to stop him suffering diarrhoea, then he may have had to seek alternative employment. The resulting financial insecurity associated with this future disorientation may have made it difficult for Geoff to plan for his future.

For others, there was a sense of uncertainty about their recovery after treatment which was consistent across both interviews. Lucy for example expressed a degree of uncertainty about her recovery in both the first and second interviews:

*Lucy Int 1 – “Erm and eh it's all around (pause) the death issue and you know when is that going to be cause it's that uncertainty aspect of... of... of living with cancer that you can't get an answer to”*

*Lucy Int 2 - “I've already told meself that I will give the chemo one more go (G – mmmm), erm, depending on what it is, if it's the same as the last time I think I might be having words with them and saying, na I don't kna, to me it obviously didn't work last time, what makes you think it's gonna work this time (G – mmmm). So... I think, I don't know”*

The first extract from Lucy above highlights that she feels that she is living with an uncertain future because of her cancer diagnosis, and this led to thoughts about death and dying. In the second interview with Lucy which took place after the discovery of a new tumour, uncertainty is again a key issue in how she views her recovery from cancer. The

language above highlights her uncertainty about how her cancer is progressing after her clinician discovered another tumour. Initially she says that she will give chemotherapy 'one more go', but quickly changes her mind as she feels that if it has not worked before then why would it work this time. This may be interlinked with a number of factors, as Lucy has a belief that she may not survive this latest set-back and coupled with her desire to be in control she may not want to not spend what time she has left coping with the side effects of chemotherapy. This is something which she discussed in both interviews, stating a desire for quality of life rather than quantity. Lucy therefore has experienced a decreased sense of recovery; as Geoff similarly expressed. For both participants future disorientation emerged in the second interview which may be related to this worsening sense of recovery. The experience of Lucy and Geoff suggests that there may be a link between the physical consequences of cancer and a sense of recovery. Lucy - who had continued feelings of pain in both interviews - and Geoff - who had continued feelings of pain and loss of stamina in both interviews - did not express a sense that their recovery from cancer was progressing well. For Lucy her sense of recovery had worsened as she had recently found out that she had developed a new tumour. Rob and John on the other hand expressed an increased sense of recovery in the second interview compared to the first. While they both expressed feelings of pain and fatigue in the first interview, this did not seem to be an issue for them at the second interview which could have aided their sense of recovery.

The results presented here highlight that how well a patient feels they are recovering from their cancer, can be influenced by certain factors such as physical well-being. When looking at the experiences of John and Lindsay it appears that their feelings (or sense) of recovery improved over time, and this seems to be associated with feelings of improved physical well-being. For John this was associated with a reduction in the experience of pain in his lower back resulting from his surgery, and for Lindsay it was associated with an

improvement in her breathing which she attributed to losing weight. Furthermore, Rob also seemed to associate his sense of recovery with physical fitness, in that his fitness improved, he began to feel that he was recovering well from his cancer. Even when a patient does not feel their recovery is improving over time this still seems to be associated with physical well-being. For example, Geoff did not feel that he was recovering as well as he had hoped, feeling that he will never regain the fitness and stamina he had before the operation. While Geoff's sense of recovery did not improve over time, Lucy's seemed to worsen which may be in part due to her recent scan where a new tumour was discovered near her kidney. While in the first interview she did not feel like she would ever recover from cancer due to the uncertainty around recurrence, this uncertainty over survival seemed to have shifted to her being certain that this time her cancer is terminal.

There seems to be an association between feelings of recovery and experience of fear of recurrence as for the most part those participants who expressed changes in their sense of recovery over the two interviews also experienced a change in the experience of fear of recurrence. For example, Rob expressed decreased fear of recurrence between the two interviews and an increase in his sense of recovery. Lindsay only implicitly mentioned fear of recurrence in the first interview and did not mention it at all in the second interview, and also displayed an increase in her feelings of recovery across the two interviews. Furthermore, Geoff's continued feelings that he was not recovering physically coincided with the expression of fear of recurrence in the second interview. Lucy's sense of recovery seemed to decrease across the two interviews and her fear of recurrence was replaced by fear of progression after the discovery of a new tumour. The only exception was John who despite feeling that he was recovering well in both interviews, expressed fear of recurrence in the second interview which was not explicitly expressed in the first. Furthermore, with reference to the previous sub-theme there appears to be a connection between a sense of

recovery and a patient's ability to look ahead and plan for their future. The results in this sub-theme further highlight that numerous aspects can lead to a disrupted view of the future such as functional impairment, fear of recurrence and recurrent thoughts related to cancer. They also emphasise that future disorientation can impact on a number of areas of a patient's life such as occupation and future planning.

The use of effective coping strategies seems to be associated with a feeling of improved recovery over the course of the two interviews. Problem-focussed coping strategies, such as increasing physical activity, seem to result in a reduction in fatigue and pain, and an increased feeling of recovery. The continuous use of certain forms of religious coping (deference) also seems to be associated with better adjustment and a sense of recovery, supporting findings in the literature (Thune-Boyle et al, 2006).

### **7.3 Life on hold**

Another way in which living with and beyond cancer can impact on a patient's view of the future is through a sense of putting their lives on hold. This can manifest itself in a number of ways, for example having to cancel or re-arrange social activities because of hospital or clinical appointments, or patients may be left with a feeling that they are not enjoying their lives at present. Like the other sub-themes presented within this chapter, there were some participants for whom this feeling seemed to be a continuing problem, whereas for others this only manifested in one of the two interviews. The following quotes provide an example of on-going feelings of placing your life on hold:

*Lucy Int 1 - "Every night going to bed and thinking, is this you know is this the last night am I not going to wake up in the morning and stuff like that and it, it was a horrible sort of way to exist and I felt as though I was just going alongside of life I wasn't living it"*

*Lucy Int 2 - "I was a bit miffed because (CNS) had contacted me about the away day for the mindfulness and I explained to her what was happening and erm, and I had even gone with (partner) to find out where it was at so that I*

*could find it (G – yeah) and I was in bloody hospital wasn't I, having the shunt put in, so I didn't get"*

Looking at the extract from Lucy's first interview there is a sense that putting your life on hold can be related to feelings of an uncertain future as a result of a cancer diagnosis. This is evidenced when she discusses her feelings of uncertainty around whether or not she was going to wake up each morning and this contributed to a feeling that she was going alongside of life rather than fully engaging with it. This would suggest that recurrent thoughts related to cancer were contributing to her feeling that her life was on hold as she discussed having these feelings most nights. The continuous worry about whether or not she was going to die would make looking ahead to her future difficult to achieve. The second quote from Lucy highlights that even when a participant does feel comfortable making plans they can often be forced to change them due to pending hospital appointments. This can then lead to feelings of putting your life on hold while recovering from a cancer diagnosis. The above quote gives the impression that Lucy is frustrated at postponing or cancelling her plans due to appointments at the hospital. This feeling of frustration at cancer getting in the way of her living her life may contribute to her feeling that her life is on hold while she begins another cancer journey and may in turn prevent Lucy from feeling comfortable looking ahead to her future.

For the most part, feeling that you have put your life on hold due to cancer was only expressed by patients at the second interview with the exception of Rob. For Rob these feelings have continued into the second interview, he had to put a lot of plans on hold having retired just prior to being diagnosed and felt that he did not get to do some of the things he had planned:

*Rob Int 1 - "Devastating at first (Grant – in terms of?) Cause I retired at 57 a week after me 57<sup>th</sup> birthday and I'm thinking fantastic, I've got 25 years of retirement to do whatever I want, and 2 and a half years later I'm having surgery for bowel cancer. Which I was just, completely flattened us yeah and*

*what you're looking for really is support, and I just didn't seem to be getting any. Yeah you just go through this process, you have a scan, you have another scan, you have your surgery, it's just like a conveyer belt of processes you go through"*

*Rob Int 2 – "No, no I haven't not done anything I wanted to, er it was a bit awkward when I was having the chemo because you know, couldn't really go out in case you needed to go to the loo so I mean you can take medication but eh, it was a bit restricting during that 6 months, but it didn't really stop us doing anything I wanted... Well my wife's taken voluntary redundancy with retirement at the eh end of June, so she is going to be retired eh so we'll be able to do whatever we want, we're not sort of limited to when she is off"*

The idea that patient's put their lives on hold while they are recovering from their cancer diagnosis is further emphasised by Rob in his first interview where he describes feeling devastated about the timing of his diagnosis coming so soon into his retirement. When he says that he felt he would have 25 years to do whatever he wanted and then he is having surgery for bowel cancer it suggests that he feels his diagnosis has restricted this ability to do whatever he wants. However the second interview highlights that while Rob was initially devastated about the timing of his diagnosis, he does not feel that it has stopped him from doing anything that he wanted to do. However, Rob then goes on to discuss that he did not feel comfortable venturing too far from the house while he was undergoing treatment for chemotherapy in case he had need of the bathroom, suggesting that he was restricted in what he could do for a limited time. Furthermore, there is a suggestion that putting his retirement plans on hold was not solely due to his cancer diagnosis as he states that now that his wife is retiring they will not be restricted in when they can do things such as go on holiday. This example of Rob draws clear parallels with the literature on future disorientation as discussed in Chapter 2, where a patient's taken for granted future is disrupted and their illness needs to be incorporated into their new future (Brearden, 1997; Maughan and Clarke, C. L., 2001; Roberts and Clarke, C. L., 2009).

In the first interview John stated that he did not feel that he had problems making future plans and was quite happy booking holidays, this remained evident at the time of the



second interview as was highlighted in the previous sub-theme. However, the quote below suggests that perhaps at some point in the past he did put things off while he felt he was still recovering, again suggesting that this is not a permanent phenomenon but affected by a number of factors:

*John Int 2 - "Yeah totally, yeah just carry on as normal, I mean we had said last year, it was basically the year from hell but the things that we went through and all that, even though with everything turned out fine at the end of the day er just basically said after last year we would make this year 'us year' sort of thing, do what we want, when we want and just go for it, holiday when we want, and feel like we don't hold back"*

When John says 'not hold back' this suggests that he did hold back on making plans in the past. This was perhaps affected by a number of factors, in the last interview John had some concerns over his career and perhaps did not feel in a financial position to be making any long term plans such as holidays. However, when he talks about 'the year from hell' this would suggest that he was talking about his diagnosis and therefore that his holding back was due to cancer and he was perhaps more concerned with recovering than he was with planning ahead. The experience of John also emphasises that positive coping strategies may help to reduce feelings of future disorientation. While he may have initially felt that he was putting his life on hold, now that he has adapted to life with a stoma and resolved his employment concerns, he no longer has feelings that he is holding back.

The above results highlight that a diagnosis of cancer can lead to a sense of frustration, or devastation, that you have had to put your life on hold because of treatment or functional impairment associated with cancer. These feelings however may only be temporary and appear to be associated with the impact of cancer and how well a patient adjusts to their life following treatment. For example both Rob and John experienced feelings of fatigue and pain respectively in their first interviews which seemed to coincide with their feeling that they had put their lives on hold as a result of cancer. By the time of the second interview

Rob was feeling fitter and healthier and was no longer feeling anxious, whereas John was no longer experiencing pain and discomfort. With both John and Rob no longer expressing feelings that their life was on hold in the second interview suggesting that as the impact of cancer lessens over time, patients may no longer feel the need to hold back or postpone making plans for their future. This is further evidenced by the experience of Lucy who continued to express feelings that her life was on hold in both interviews and seemed frustrated that cancer was getting in the way of her living her life. While the impact of cancer seemed to improve over time for Rob and John, this was not the case for Lucy. Her continuing expression of feelings of anxiety, recurrent thoughts related to cancer, experience of pain and discomfort and having developed a new tumour may all be contributing to her feeling that she has had to place her life on hold.

While the impact of cancer may contribute to feelings that a patient is putting their life on hold, there also appears to be a relationship between positive coping strategies and a reduction in feelings that your life is on hold. Lucy continually adopted negative coping strategies over her cancer journey such as avoidance and emotional suppression, and also abandoned her use of religious coping upon the development of a new tumour. The use of positive coping strategies have been shown to increase adjustment to illness (Llewellyn et al, 2007; Tarakeshwar, et al 2006; Thuné-Boyle et al, 2006) and therefore her use of negative coping strategies may have contributed to ongoing consequences of cancer and subsequently a feeling that she has placed her life on hold. Lucy also felt that she was not receiving support from her close family members and studies have shown that emotional support can also result in better adjustment (Bloom and Spiegel 1984; Bloom et al, 2001 & Michael et al, 2002). Therefore by not receiving emotional support from her family members she is possibly missing out on another factor which could reduce the impact of her cancer. John on the other hand has continued to adopt positive problem focussed

coping strategies in relation to the impact of his cancer. He has adapted well to the fact that he will have a permanent stoma and has taken steps to minimise its impact on his life, for example changing his diet when he experienced a blockage in his bowels. He also seemed to have received a great deal of support from his wife and step-children and the combination of receiving functional support and positive coping strategies may have helped him feel a reduction in the impact of his cancer. Rob also appears to be adopting positive coping strategies. In order to overcome his feelings of lethargy he has increased his physical activity by joining a gym and has also joined a support group to try and lose weight. In addition, he dealt with his feelings of anxiety by reporting them to a clinician and discussed his prognosis which was causing him to worry. By adopting these positive coping strategies, Rob felt fitter and had a reduction in his feelings of lethargy by the time of the second interview and was also no longer feeling anxious. This reduction in the impact of his cancer therefore may have led him to feeling less like he had to postpone his future and that his life was on hold. In summary the above examples suggest that the use of positive coping strategies and drawing on functional support can help to reduce some of the impacts of cancer which may lead to patients feeling that their life was on hold. A failure to adapt to the impact of cancer can however be distressing and lead to feelings of frustration which were expressed by Lucy.

#### **7.4 Summary**

The results presented in this chapter highlight that experiencing future disorientation can have a number of consequences for patients. While the literature identified that future disorientation may cause distress in relation to infertility (Maughan & Clarke, C. L. 2001; Roberts and Clarke, C. L., 2009), and occupational concerns (Charmaz, 1994; Rasmussen & Elverdam, 2008; Verdonck-de Leeuw, 2010), a number of other potential consequences of future disorientation emerged from the interview transcripts. An inability to look ahead

and plan for the future is one area of a patient's life that appears to be compromised by future disorientation. A number of participants in this study expressed that they were uncomfortable making plans for their future as they were concerned they would be too ill to fulfil said plans. This seems to be associated with a fear of recurrence as most participants who discussed feeling unable to make future plans, in one or both of their interviews, also tended to express fear of recurrence in the same interview. This then could cause patients to either cancel plans they had already made, or avoid making plans in case they are told that their cancer has recurred and they need to cancel them. Even when a patient does feel comfortable making plans for their future, if they have any scheduled follow up appointments this can cause them to temporarily hold off from making plans until they have received results. Evidence suggests that fear of recurrence can be long term, although it tends to reduce over time (Ghazzali et al, 2012 & Savard & Iver, 2013). The evidence presented in Chapter 7.1 would suggest that as a patient's fear of recurrence reduces, their ability to look ahead and plan for the future may return. For the most part those patients who expressed reduced feelings of future disorientation between the first and second interviews continued to feel comfortable planning for their future. Whereas those who have experienced greater levels of fear of recurrence in the second interview tended to discuss an inability to look ahead to their future. Moreover, referring back to Chapter 5.1.1 there was some evidence that the use of positive coping strategies could reduce the experience of fear of recurrence. Coping strategies, for example problem focussed coping strategies, could lead a participant to identify solutions for their fear of recurrence such as changing their diet to alleviate symptoms which have lead to these fears. Furthermore, those patients who had access to emotional support may be more likely to report any recurrence concerns to a clinician and thus alleviate their fears.

While fear of recurrence tended to lead to an inability to look ahead and plan for the future, the physical impact of cancer, such as feeling fatigued or experiencing pain and discomfort could lead to a patient feeling that they were not recovering from their cancer. The experience of physical pain and fatigue has been reported as a common concern for patients who have been treated for cancer (Dunport, et al., 2014; Kim et al, 2008; Ramsey et al, 2002) and a similar trend was found in the current study. Those who discussed feeling lethargic and having experienced pain or discomfort tended to express feelings that they were not recovering well from their cancer. While a number of participants expressed these feelings in the first interview, by the time of the second interview these feelings seemed to have eased off for most participants. The evidence in Chapter 7.2 would suggest that feelings of recovery can begin to emerge over time as feelings of fatigue, pain and discomfort reduce. For those participants who did experience a reduction in these feelings, there seemed to be an increase in their sense of recovery over time while for participants who continued to feel fatigued or continued to experience pain and discomfort, there was no increase in their sense of recovery over time. With reference to the themes explored in Chapter 6, there is some evidence that the use of coping strategies may help in reducing feelings of fatigue and pain and discomfort which in turn may lead to an increased sense of recovery. Those participants who adopted problem focussed coping strategies such as increasing their physical activity to reduce feelings of fatigue, or by reporting feelings of pain to a clinician, tended to see a reduction in these feelings over time. However, those who adopted negative coping strategies, such as avoidance, tended to continue to experience feelings of fatigue or pain and discomfort.

The final consequence of the experience of future disorientation which emerged from the interviews was a feeling that a patient was placing their life on hold because of their cancer diagnosis. Patients described the feeling that they had to put their lives on hold because of

cancer as frustrating or devastating. From the evidence presented above it is not clear what factors lead to feeling that you are placing your life on hold. Lucy experienced recurrent thoughts related to her cancer and fears of an uncertain future which seemed to cause her to feel that she was placing her life on hold. Rob also seemed to relate feeling that his life was on hold with an uncertain future. However, after discussing his feelings with a clinician and being told that his prognosis looked good, these feelings seemed to reduce over time. By the time of the second interview, Rob was looking forward to spending more time with his wife after she retires. John on the other hand seemed to relate placing his life on hold to functional impairment and as he adapted to his stoma over time these feelings eased off and he and his wife are planning on doing a lot of things over the next year that they had always wanted to do. Like future planning (7.1) and feelings of recovery (7.2) there is some evidence in the transcripts to suggest that positive coping strategies are associated with feelings that you are placing your life on hold. Both Rob and John tended to adopt problem focussed coping strategies such as reporting concerns or accepting functional impairment and found ways to adapt their new lives post cancer treatment. Lucy on the other hand tended to avoid thinking about her cancer and tried to suppress any negative emotions. However, while these strategies may lead to worse adjustment to illness (Bloom and Spiegel, 1984; Derogatis, et al, 1979), the onset of a new tumour and the realisation that she was beginning another cancer journey may also be a factor in her continuing feelings that cancer is causing her to place her life on hold.

## **Chapter 8 – Discussion**

### **8.1 Introduction**

The following chapter outlines the findings of this study in relation to the research aims which were outlined in Chapter 2.8 and the wider literature. The results generated by this study have led to the development of the conceptual framework presented at the end of this chapter which is used to highlight contributory factors to the experience of future disorientation, which factors may reduce the experience of future disorientation and what the consequences of future disorientation are. There are a number of theories which have been used to explain the experience of cancer, the most common of which is perhaps Biographical Disruption (Bury, 1982). However, this theory does not adequately represent the experience of cancer patients who have finished treatment for cancer as it was originally proposed as a theory to explain the experience of chronic illness. While the WHO now classes cancer as a chronic illness, it is unlike other chronic illnesses in that it is a disease with an acute phase of illness followed by long term consequences of treatment for the disease. Therefore, there are elements of the experience of cancer which are not adequately explained by theories such as biographical disruption (Bury, 1982) such as fear of recurrence and dealing with sexual dysfunction, and uncertainty about the future. This thesis presents a framework of the experience of future disorientation which is shaped by the various physical and psychological consequences of cancer and its treatment. While many factors in this framework have been explored in the past, this is the first to look at the impact that these symptoms can have on how a patient views, and plans for their future. Building on the work of Maughan and Clarke, C. L. (2001), and Roberts and Clarke, C. L. (2009) this thesis has highlighted that future disorientation is something which can affect people with different tumour types, can persist for a long period of time after diagnosis, and may be caused by a multitude of factors.

The results also highlight that future disorientation is not just a consequence of treatment for gynaecological cancer, but that men and women treated for colorectal cancer can also be susceptible to future disorientation. Following a summary of the results presented below, the strengths and limitations of this study will be outlined. It felt appropriate when articulating the main strengths and limitations of this thesis to do so in the first-person and certainly J. A. Smith et al (2009, p. 41) would argue that the researcher should be willing to use the first-person when taking up a position or developing arguments. Following the strengths and limitations, the discussion will move then onto make recommendations for future research in this area leading onto a conclusion to the thesis.

## **8.2 Summary of results in relation to the wider literature**

### **8.2.1 Fear of recurrence contributes to the development of future disorientation**

The results presented in this thesis indicate that fear of recurrence is a contributing factor which can disrupt a patient's view of the future. This was particularly the case when it came to making future plans such as having holidays with family and friends. The uncertainty associated with fear of recurrence appeared to be the main contributory factor to this as participants expressed fears that they would be too ill in the future and therefore did not want to make future plans in case they had to cancel or amend these plans. However for most participants this seemed to be short term and related to either the experience of what are perceived to be recurrent cancer symptoms or impending follow up appointments. In the case of symptoms, fear of recurrence seemed to reduce if the participants reported their symptoms to a clinician and were subsequently told that the cancer had not recurred. Evidence from the literature suggests that fear of recurrence is a common, long-term concern for patients who have been treated for cancer (Handsichel, et al. 2012; Herschbach, & Dinkel, 2014; Humphris, et al. 2003; Im, et al. 2008; Northouse, et al. 1999; Savard & Ivers, 2013) yet it is not a consistent concern for all participants



(Ghazalli et al, 2012; Llewellyn et al 2008; Savard & Ivers, 2013) suggesting that while patients may experience fear of recurrence at certain times it is not always a salient concern. This seems to also be the case for the participants discussed in this study as while fear of recurrence was reported by most participants their fears seemed to peak around clinical appointments and in the presence of triggers such as symptoms.

The results of this study also highlighted that other cancer related fears may contribute to disrupted views of the future in adults living with and beyond cancer. Fears associated with an uncertain future for example appeared to be related to a feeling that participants were placing their life on hold. One participant described her concerns about not waking up each morning as leaving her feeling that she was going alongside of life rather than living it. Another participant described feeling devastated at the thought of their cancer diagnosis and discussed how it had prevented him from enjoying retirement and fulfilling all of the plans he had made for his post-working life. This theme also highlighted an interesting issue not directly related to future disorientation around the use of the word death. Most participants who talked about an uncertain future avoided use of the word death choosing instead to use expressions such as “I won’t be here at Christmas” or “Will I wake up in the morning?” Interestingly there did not appear to be a relationship between fear of recurrence and fear of an uncertain future which suggests that just because a patient is concerned that their cancer will return does not mean that they feel they will die because of cancer recurrence.

The final cancer related fear reported by participants was the fear of the impact of cancer. This seemed to cause concern for some men in this study who expressed concern that the impact of their cancer could lead to problems with them returning to work. This was especially the case when patients encountered functional impairment as a result of their treatment. However, the results also highlight that the role of the impact of cancer on

future disorientation is something that may not be experienced by everyone and may depend on the occupation of the patient. John for example was concerned about returning to work as he felt uncomfortable working in the catering industry with a stoma and was considering alternate careers. Paul, had concerns about his future employment as he felt less physically fit after treatment for cancer which impacted on how well he felt he could carry out his role as a gardener. Geoff has experienced diarrhoea since his treatment which made working as a delivery driver with no access to a bathroom particularly problematic. Had any of these participants had different jobs which their functional impairment did not impact on then it is possible that they would not have experienced future disorientation in this regard. However the results do highlight that this is an important aspect of a patient's life which may be impacted on by future disorientation. The corresponding financial concerns which may accompany this form of future disorientation may have a knock on affect for other consequences of future disorientation such as planning for the future.

To summarise, the literature review identified that fear of recurrence may contribute to the development of future disorientation and the results presented in this thesis support this. However, other cancer related fears also emerged from the data which can contribute to future disorientation. This led to the inclusion of cancer related fears in the first strand of the conceptual framework highlighted in Chapter 8.9 which relates to potential causes of future disorientation.

### **8.2.2 Various impacts of cancer will contribute to the development of future disorientation**

While the above section detailed how cancer related fears can lead to the experience of future disorientation, this section will summarise the results in relation to how other impacts of cancer can lead to the experience of future disorientation. Consequences of a cancer diagnosis and treatment also appear to influence how a patient makes sense of and

come to terms with their new future after a cancer diagnosis. For example a number of participants expressed feelings of anxiety which were related to upcoming hospital appointments which may lead to a temporary inability to look ahead and plan for the future while the patient awaits the results of their scan. This may result in a temporary disruption to views of the future, the consequence of which may be a temporary inability to make plans. Due to an inability to adapt to a life without being able to have children, Rachel tends to avoid agreeing to social situations where she knows that young children will be present as she knows this will cause her to become upset. Lucy also experienced a number of consequences of cancer such as feelings of anxiety and of having no control over her life since her diagnosis from cancer. This seemed to be associated with her sense that her life was on hold. Thus as time progressed she began to feel uncomfortable making plans for her future and discussed pulling out of a trip with friends as she believed she would be too ill and did not want to ruin anyone else's trip.

Functional impairment is another consequence of cancer and cancer treatment which may contribute to feelings of future disorientation and seems to be closely related to the fear of the impact of cancer discussed above. While the fear of the impact of cancer seemed to specifically lead to concerns about future employability, functional impairment such as pain and fatigue seemed to also lead to disrupted views of the future. However this experience may only be temporary, for most participants in this study their experience of fatigue and pain seemed to reduce after the first interview and feelings of recovery had begun to emerge by the second interview. This was the case for Rob and Lindsay who both spoke of easily becoming tired when carrying out tasks that normally would not require a great deal of physical exertion such as doing housework or walking to the shops. However, both patients then described in the second interview that they felt much fitter and this coincided with feelings that they were recovering from their cancer. For those patients

who continued to experience lethargy and pain at the time of the second interview there was a continued feeling that they were not recovering well from cancer. An interesting point which arose in discussions around recovery was the potential role of physical activity and losing weight in reducing feelings of future disorientation. Rob made a conscious effort to lose weight and increase his physical activity after his surgery and this may explain why he now feels fitter and healthier, Lindsay also made a conscious effort to lose weight. Geoff and Lucy both felt that their physical recovery was not progressing and both had given up physical activity after their surgery as they felt that they were unable to regain the levels of fitness they had prior to their diagnosis. While John generally felt comfortable with his stoma, his reluctance to wear a bag means that he avoided partaking in social activities of which he has had no prior notice. He feels uncomfortable going out without emptying his bowels through irrigation and prefers to know in advance if he is going out so that he can be prepared. Research has suggested that symptom clusters may be an important factor in how patient's adjust to an illness such as cancer (Dodd et al, 2001a, Dodd et al, 2001b; Henoch & Lövgren, 2014; Maguire, R. et al, 2014; Wang, Tsai, Chen, Lin, & Lin, 2008) and this is supported by the evidence presented in this thesis as those participants who suffered multiple consequences of cancer and its treatment such as sexual dysfunction, anxiety, fear of recurrence, and occupational concerns were more likely to express feelings of future disorientation.

In summary, the various impacts cancer and cancer treatment can have on a patient's life were identified after the literature review as potential causes of future disorientation (Ashing-Giwa et al., 2009; Gao et al, 2010; Glanz & Lerman, 1992; Irwin et al, 2012; Jansen et al, 2010; Klostevsky et al, 1999; Nordin et al, 2001; Osborn et al, 2006). The results which emerged from the interviews in this study have highlighted that factors such as anxiety, functional impairment, and feeling a loss of control can all contribute to feeling

that participants are not recovering from cancer, and also affect their social life. Furthermore, those participants who expressed multiple symptoms relating to cancer and its treatment appeared to have more severe consequences of future disorientation, thus supporting evidence in the literature that those who suffer from symptom clusters have poorer adjustment to cancer (Hench & Lövgren, 2014; Maguire, R. et al, 2014; Wang, Tsai, Chen, Lin, & Lin, 2008).

#### **8.2.4 Future disorientation can result in impaired ability to plan for the future, concerns about ability to return to work/change career as well as concerns about infertility**

Previous research into the experience of future disorientation highlighted that an inability to come to terms with a loss of one's anticipated future due to the impact of cancer could be distressing. Although this research mainly focussed on women who could no longer have children due to a hysterectomy (Maughan & Clarke, C. L. 2001; Roberts & Clarke, C. L. 2009;), infertility is also a real concern for men treated for cancer. Men therefore may also be susceptible to future disorientation if they have not had all of the children they had planned on having (Den Ouden et al, 2012). Furthermore, the review of the literature highlighted that functional impairment due to cancer treatment can have an impact on patients' ability to return to work (Bottorf et al, 2008; Carr & Kemmis, 1986; Kiserud et al., 2014; Nilsson et al, 2011; Ussher et al, 2006). The resulting financial uncertainty associated with occupational concerns such as feeling that you may not be able to return to work could therefore contribute to feelings of future disorientation by making it difficult to plan for the future. The data presented in Chapter 5.2.1 and 5.2.5 seem to support the idea that future disorientation does not only lead to infertility concerns in women but can affect a patient's life in a number of ways.

Three participants in this sample had been left infertile as a consequence of their cancer treatment; Lucy and Rachel had hysterectomies to treat gynaecological cancer while Rob was left unable to ejaculate as a consequence of surgery for colorectal cancer. However, of these participants only Rachel was childless at the time of her surgery and had actively been trying to have children. Rachel has experienced feelings of future disorientation as she has struggled to come to terms with a future life without children of her own, and this experience seems to be long term as it was discussed by Rachel in both of her interviews. Lucy and Rob on the other hand while being infertile did not express any feelings of future disorientation in relation to their infertility. However, Lucy and Rob both have grown up children and realistically were not going to have any more children, therefore this may be why infertility has not contributed to feelings of future disorientation. These results support the findings of Maughan and Clarke, C. L. (2001), and Roberts and Clarke, C. L. (2009) as they further highlight that infertility can lead to the experience of future disorientation in women who have not had all of the children they had planned on having which can result in feelings of distress. They also highlight that men living with and beyond cancer may be susceptible to feelings of future disorientation as while Rob did not experience future disorientation in this regard, a younger man who had not had all of the children he wanted at time of diagnosis may develop feelings of future disorientation.

Green and King (2009) highlighted that patients who have suffered from a stroke may be left unable to plan for their future, and like patients who have been treated for cancer they may be unprepared for their illness and experience fears of recurrence (Townend et al, 2006). This suggests that people living with and beyond cancer may also be left feeling uncomfortable or unable to plan for their future. A number of consequences of cancer emerged from the interviews which may contribute to the experience of future disorientation such as fear of recurrence which was discussed above, functional

impairment, and may also be linked to the occupational impact of future disorientation. As discussed previously, fear of cancer recurrence seemed to cause a temporary inability to make plans for the future when a patient has an upcoming follow up appointment or when they experience symptoms that they believe to be recurrent cancer. By attending clinical appointments these fears can be alleviated and a sense of the future seems to return. The results presented in this thesis also point to functional impairment as a factor which can cause feelings of future disorientation. John for example no longer feels comfortable making spur of the moment social plans as he prefers having time to irrigate his stoma before leaving the house whereas prior to his cancer diagnosis he would have been happy to make last minute plans. Evidence in the literature suggests that people living with and beyond cancer face a number of barriers to returning to work after treatment (Bottorf et al, 2008; Carr & Kemmis, 1986; Kiserud et al., 2014; Nilsson et al, 2011; Pélissier, et al, 2014; Ussher et al, 2006). While the role of functional impairment in terms of the occupational impact of future disorientation was discussed above (8.3.2), there was also a suggestion in the results section that occupational concerns may lead to patient's not being able to make plans for their future. If a patient feels that they are not able to return to the job they held before diagnosis then this can make them uncomfortable making any plans as the financial uncertainty of associated with potential unemployment would make planning for the future difficult.

#### **8.2.5 The experience of future disorientation will be long term**

One of the main objectives of this study was to explore whether or not the experience of future disorientation was long term given that previous studies had only interviewed patients on one occasion. A number of the consequences of a cancer diagnosis and treatment outlined in the literature review chapter appeared to be experienced long term such as fear of cancer recurrence (Savard & Ivers, 2013), occupational concerns (Mehnert,

2011) and anxiety (Charmaz, 1994). Therefore as these were identified as factors which may contribute to the experience of future disorientation then it is likely that the experience of future disorientation will equally be long term. The long term impact of future disorientation has been touched on in other sections of this discussion chapter but is explored in more detail here. The results presented in this study seem to suggest that future disorientation may be a long term consequence of cancer, however some of the consequences of future disorientation only seem to be experienced short term, or sporadically throughout the cancer journey.

The work of Maughan and Clarke, C. L. (2001) and Roberts and Clarke, C. L. (2009) into the experience of future disorientation amongst women living with and beyond cancer was the primary inspiration for the development of this conceptual framework. They surmised that if a patient had not had all of the children that they had wanted to at the time of their diagnosis then this could lead to future disorientation; failure to adapt to this disrupted view of the future could be a distressing experience for those affected. Three participants in this study were left infertile as a result of their cancer treatment, one of whom had planned on having children prior to her treatment. She found it difficult to accept that her vision of a future with children is no longer achievable leading to feelings of future disorientation which she expressed in both of her interviews. This would suggest that when future disorientation is caused by infertility that these feelings can persist long after treatment.

However, other aspects of future disorientation were not long term for all of the participants in this study. While being uncomfortable making plans for the future may be a long term consequence of cancer, it did not appear to be a constant consequence for participants in this sample. Of those participants who expressed feeling uncomfortable making plans for their future only one did so consistently across the two interviews. Other



participants seemed to only express these feelings at one of the two interviews, and it seemed to be associated with fear of recurrence related to symptom experience or impending follow up appointments. As discussed in Section 8.3.1 evidence in the literature suggests that the experience of fear of recurrence is common amongst cancer patients and has been identified as something which is not a consistent concern for patients. The evidence from this sample points to fear of recurrence being a contributing factor to the experience of future disorientation then it stands to reason that reducing the experience of fear of recurrence can also reduce the impact of future disorientation. This is something which could perhaps be studied in future research.

Occupational concerns were also identified in the literature as a consequence of cancer which could be long term and lead to the experience of future disorientation as patients face a number of barriers which may prevent them returning to employment (Bottorff et al, 2008; Carr & Kemis, 1986; Ussher et al, 2006). The evidence presented in this thesis would suggest that even when a patient is able to return to work after treatment for cancer they may still experience future disorientation which may lead to them seeking out alternate employment. A number of patient's discussed how functional impairment was impacting on their ability to carry out their work, with one specifically saying that he was seeking alternative employment as he felt uncomfortable carrying out his current role. Other patient's discussed a lack of confidence and a belief that their bosses would think they are no longer able to carry out their job. This may hint at underlying belief in themselves that they are no longer able to work as effectively in their current occupations. However, while this may be cause patients to experience future disorientation in the long term, the results presented here also show that if a patient finds a way to adapt they can begin to regain confidence in themselves and feelings of future disorientation may fade.

### **8.2.6 – Effective coping strategies can minimise or prevent the experience of future disorientation**

The above sections have summarised the results chapters in terms of which factors may contribute to feelings of future disorientation. The following two sections focus on factors which may help reduce the impact of future disorientation. While a number of theories have been presented which explain coping strategies in terms of health, the author of this thesis felt that the CSM was the most appropriate when looking at a cancer population (Leventhal et al, 1980). This model states that an individual will develop cognitive and emotional interpretations of a health threat, they will then develop an action plan, before appraising the action plan. The action plan can consist of either positive or negative strategies with research showing that negative coping strategies such as avoidance could lead to depression and anxiety (Deragotis et al, 1978; Llewellyn et al, 2007; Llewellyn et al, 2008). The data presented in the results chapters above seem to support the view that coping strategies can also impact on the consequences of future disorientation. Patients who adopted negative coping strategies such as deference religious coping, avoidance, or emotional suppression seemed to experience more consequences of future disorientation than patients who adopted more positive approaches. Furthermore, evidence in the literature has suggested that the patients experience of cancer and searching for meaning to their experience can influence how well they adjust to cancer (Park et al, 2008; Park et al, 2010; Morrill et al, 2008; Cordova et al, 2001; Davis et al, 1998; Lee, 2008). However this is only an effective coping strategy if the patient attaches meaning to their experience (Park et al, 2008) which can result in post-traumatic growth, which in turn has been related to better adjustment to cancer (Park et al, 2010). Within this present study, those participants who attached meaning to their experience such as positive changes to their lives were not as affected by future disorientation as those who failed at attach meaning to their experience. However, the meanings attached to experience may be influenced by

other factors such as recurrent cancer or anxiety can impact on meanings made and their adjustment to cancer.

The potential relationship between coping strategies and consequences of future disorientation is perhaps best exemplified by the contrasting experiences of John and Rachel. In the first interview John seemed to be experiencing future disorientation in relation to his permanent stoma post-treatment. The consequence of this was that he no longer felt confident working in the catering industry, feeling that it was unhygienic to wear a colostomy bag while he was serving food. This had the potential to be a long-term consequence of his cancer treatment if he was unable to find a suitable alternative career. However by adopting a positive coping strategy, John seems to have formulated a positive response to his stoma by researching an alternative to wearing a bag, mainly irrigating the stoma every couple of days thus negating the need to wear a bag. The result of this approach was that by the second interview John was still working in the catering industry and had moved to a more permanent position, and was no longer feeling uncomfortable working in this arena. The experience of John complements the research by Huizink et al (2002) and D’Zurilla and Nezu (2010) who state that problem focussed coping can reduce distress, and highlights that it can also reduce the impact of future disorientation. Alternatively, Rachel continued to express feelings of future disorientation in both the first and second interviews in relation to infertility, which had a number of consequences such as an inability to come to terms with not having children of her own, and reluctance to be around young children. In terms of coping, Rachel seems to avoid talking about her infertility concerns for fear that it will upset her husband and parents, and she also feels that other people do not understand her feelings and thus avoids discussing them. While John found a way to adapt to his future disorientation thus reducing its impact Rachel continued to avoid dealing with her negative feelings around infertility by keeping them to herself and this could potentially be prolonging the impact of future disorientation. The

literature highlighted that negative coping strategies were correlated with the experience of anxiety and depression (Deragotis et al, 1978; Llewellyn et al, 2007; Llewellyn et al, 2008) and evidence presented in this thesis would suggest that negative coping strategies may also prolong the impact of future disorientation.

#### **8.2.7 – Functional support can minimise or prevent the experience of future disorientation**

Social support was identified in the literature review as something which could reduce the impact of some of the consequences of cancer such as anxiety, as long as the support was functional and emotional (Bloom & Spiegel, 1984; Bloom et al, 2001; Michael et al, 2002). Therefore it was anticipated that those patients who could draw on functional and emotional support would not experience future disorientation to the same extent as those who could not, if indeed they experienced it at all. The data presented in the results chapters above seem to provide evidence in support of this statement. While a number of participants discussed feelings relating to a disrupted view of their future for some this did not seem to be long term. Those participants who felt that they received adequate functional support seemed to experience a reduction in their experience of future disorientation whereas those who felt that they had a lack of functional support seemed to continue to experience a disruption in their views of the future. This is perhaps best evidenced by the experiences of Lucy and Rachel, both of whom discussed a lack of family support stating that they felt that they could not communicate any concerns with their spouses. Rachel in particular highlighted how a lack of support can be associated with the consequences of future disorientation as she discussed that she did not like talking about her infertility with her husband as she felt he might blame himself for having a vasectomy. As the main consequence of her future disorientation is an inability to come to terms with

her infertility this suggests that a lack of emotional support may be preventing her from adapting to a new future without children.

When contrasting the experience of Lucy and Rachel with John's further evidence for the potential buffering effect of functional support emerges. While in the first interview John felt the impact of future disorientation in relation to his occupation, in the second interview he had overcome these feelings and this may be in part due to his levels of perceived support. John discusses in both interviews that his wife has been a constant source of support for him and when he began to have symptoms which may have indicated recurrent cancer she convinced him to get them checked. This may have helped John avoid a consequence of future disorientation by alleviating any fears of recurrence he may have developed which could have caused a disruption to his view of the future. Furthermore, John also described in both interviews that he felt the level of support he received from the hospital staff was excellent. His confidence with the clinical staff may also have helped reduce feelings of future disorientation as had he not felt that he could rely on them then he may not have reported his recurrent symptoms even with his wife prompting him to do so. Bloom and Spiegel (1984) asserted that social support could reduce the impact of stressful situations and the results presented in this thesis highlight that this may also be the case for reducing the impact of future disorientation.

Furthermore, evidence was identified in the literature which suggested that supportive care provided by clinical staff could aid in adjustment to cancer and reduce the impact of sexual dysfunction, communication problems, and financial concerns (Foster et al, 2009; Ganz, 2001; Harrison et al, 2009; Harrison et al, 2011). However, supportive care was most effective when patients could build up a relationship with the clinician who delivered their follow-up appointments by seeing the same person at each appointment (Arora et al, 2011). There is some evidence presented within this thesis to support the findings of Arora and

colleagues (2011) as participants reported unhappiness at seeing different consultants each time they had a follow up appointment, and one in particular mentioned how much happier she had been once she started seeing the same clinical nurse at each of her appointments. This can be essential to adjustment to cancer, as discussed by Ganz (2001), and Harrison and colleagues (2011), physical and psychological symptoms can persist for years after diagnosis and treatment for cancer and it appears to be important to patients that they can build up a relationship with supportive care staff. Some of the issues patients need to discuss can be quite sensitive, such as sexual dysfunction, and a patient needs to feel comfortable discussing any problems they have. This has important implications for clinical practice as it would appear that any interventions designed to reduce the experience of future disorientation should be delivered by staff that the patient can trust and whom they have built up a relationship with.

### **8.3 A Conceptual Framework of factors leading to, and consequences of future disorientation**

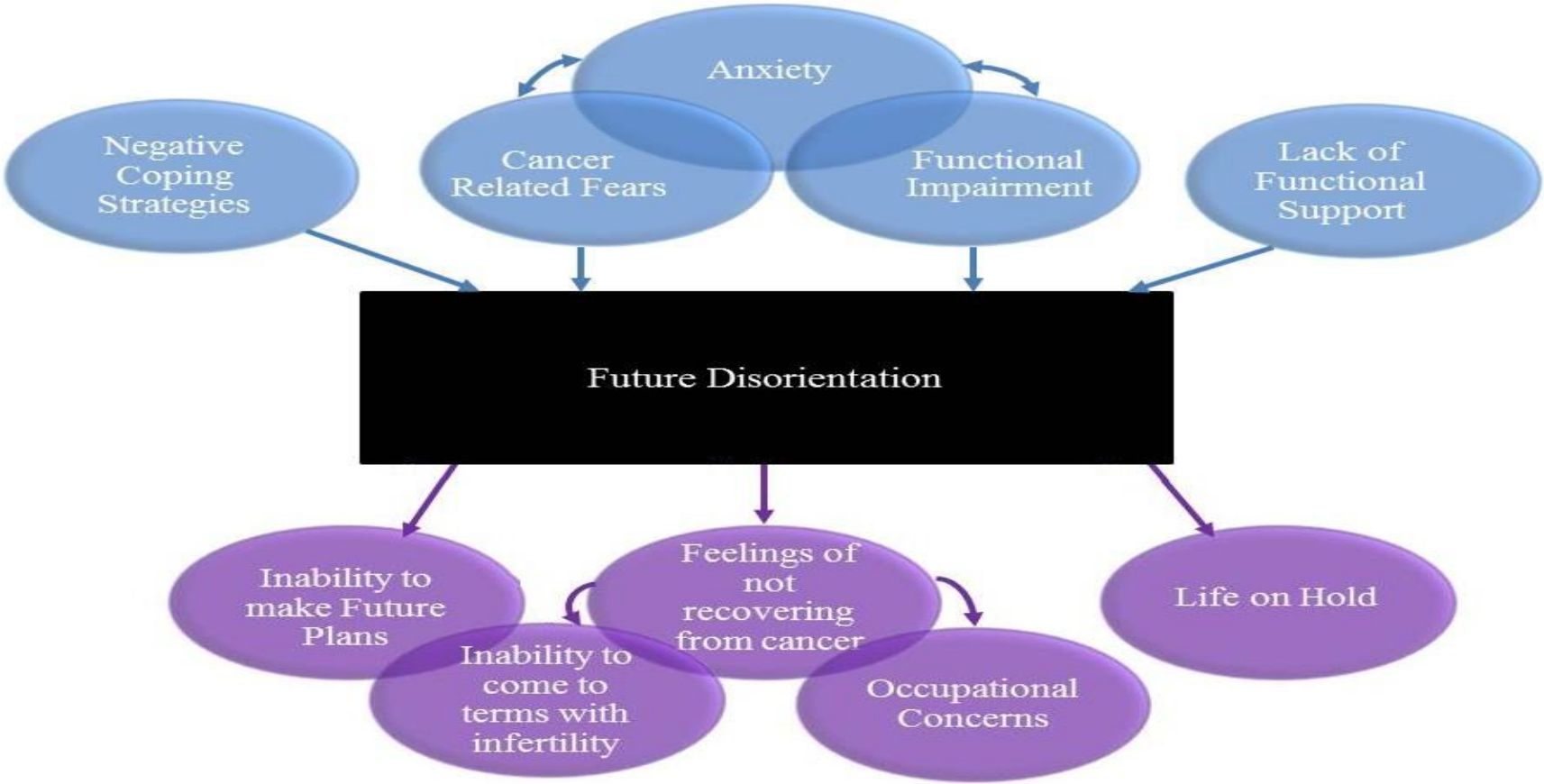
Before discussing the conceptual framework of the experience of future disorientation it is important to reiterate what is meant by future disorientation. Roberts and Clarke, C. L. (2009) defined future disorientation as the disruption that arises out of an unexpected life event such as the diagnosis of cancer. If a patient is unable to adapt to a future, which is not the one they had envisioned, then this may lead to consequences such as an inability to come to terms with infertility.

As discussed earlier, the process of developing a conceptual framework has been described as iterative, constantly moving between concept and data to develop the framework (Orlikowski, 1993). According to Yossef Jabareen (2009) a conceptual framework should be informed by a multitude of data sources, comprising concepts found in the literature, as well as the emerging results found by the researcher when investigating a phenomenon.

As such, the conceptual framework presented below (Figure 8.1) will include elements which were discussed in the literature review as potential causes of, and consequences of future disorientation. The literature review was also used to develop the interview schedule, and data which emerged from the interviews also contributed to the framework outlined below. Furthermore, McGaghie, Bordage, and Shea (2001) would argue that the purpose of a conceptual framework is to identify the research variables, and to describe the relationships between them. Therefore, the conceptual framework presented below outlines all of the variables identified in the process of this research, and the author will attempt to explain how they link together with reference to the results chapters and the discussion sections above.

The conceptual framework will now be presented, before moving onto a discussion of how the different strands are related.

Figure 8.1 A conceptual framework of the causes of and consequences of future disorientation





The conceptual framework outlined in figure 8.1 above ties together the results presented in this thesis, both from the results chapters and from the literature review, as advocated by Jabareen (2009). The framework is presented so that factors which can cause future disorientation are outlined at the top of the framework in the blue circles. The purple circles at the bottom of the framework represent the negative outcomes of future disorientation, which can arise if a patient fails to adapt to their disrupted view of the future. It is important to iterate that while many patients may experience the consequences of cancer outlined at the top of the framework, some patients will adapt to their disrupted view of the future. Subsequently they may not experience future disorientation at all, or they may only experience it's negative outcomes for a short period of time. In the paragraphs below, each of the potential causes of future disorientation are explained in relation to the literature, and the data which emerged from the interviews, while also explaining how they relate to specific consequences of future disorientation.

The literature review identified that fear of cancer recurrence could potentially lead to the experience of future disorientation (Handschel, et al. 2012; Humphris, et al. 2003; Im, et al. 2008; Northouse, et al. 1999; Savard & Ivers, 2013). The data that emerged from the interviews indicated that fear of recurrence was associated with future disorientation, however other cancer related fears also emerged. Fear of the impact of cancer, and fear of an uncertain future also appeared to be related to whether or not a participant was experiencing future disorientation. Referring to the literature, the experience of fear of recurrence is not stable across the cancer trajectory (Ghazzali et al, 2012; Hart et al, 2008); the evidence presented in this thesis supports this, as fear of recurrence seemed to peak around the time of follow up appointments, or when a patient experienced symptoms. Cancer related fears lead to one aspect of future disorientation, mainly an impaired ability to look ahead and plan for the future, something which diminished once an appointment

had been attended or once it had been established that a patient was not experiencing symptoms of recurrence.

These fears were grouped together in the results chapters under the super-ordinate theme 'cancer related fears' and led to the inclusion of this theme in the conceptual framework. The impact of cancer treatment was also identified as something which could lead to the experience of future disorientation with previous research in this area identifying that having a hysterectomy can lead to the experience of future disorientation amongst women treated for gynaecological cancer (Maughan and Clarke, C. L. 2001; Roberts and Clarke, C. L. 2009). Furthermore, evidence presented in the literature review identified that the functional impairment caused by cancer treatment may lead to a patient questioning whether or not they can return to full time employment and thus disrupting their view of the future. The results presented in this thesis support the view of Maughan and Clarke, C. L. (2001) and Roberts and Clarke, C. L. (2009) and also highlighted that infertility concerns can lead to future disorientation in males. Sexual dysfunction is a possible consequence of treatment in males diagnosed with colorectal cancer, and while testicular cancer patients were not interviewed as part of this study, it is reasonable to assume that they are equally susceptible to future disorientation. Furthermore, the literature illuminated that functional impairment can lead to barriers in patients returning to work after cancer treatment for a number of reasons, such as age at diagnosis (Carr & Kemmis, 1986) and tumours being at an advanced stage when diagnosed (Bottorff et al, 2008). The data which emerged from the results of this thesis would support this view, as consequences of functional impairment could lead patients to feel self-conscious about working with a stoma, or not feeling physically able to resume working anymore due to feeling fatigued. Functional impairment and sexual dysfunction as a consequence of cancer treatment were therefore included in the conceptual framework under the heading

‘functional impairment’. The impact of functional impairment could lead to a multitude of consequence of future disorientation if patients were unable to adapt to their new future. These are included in the conceptual framework under the heading ‘feelings of not recovering from cancer’. If patients feel unable to return to work this can lead to long term occupational concerns. Furthermore, occupational concerns could make it difficult to plan for the future if a patient feels they are unable to return to work this could lead to financial insecurity. Additionally, if a patient is unable to come to terms with their infertility, distress can occur and lead to changes in behaviour, such as avoiding situations where they may be around young children.

Anxiety was a common theme which was discussed by a number of participants in this study, the data which emerged from the interviews with patients did not point to a direct relationship with the experience of future disorientation. Rather, anxiety seemed to be related to cancer related fears and functional impairment, although the direction of the relationship was not clear from the results. A number of participants in the study discussed feelings of anxiety related to upcoming clinical appointments and in relation to experiencing symptoms which lead to an increase in fears of recurrence. However, it is not immediately clear if fear of recurrence relating to symptoms or follow up appointments led to feelings of anxiety or whether the anxiety felt relating to symptoms and follow up appointments caused an increase in the experience of fear of cancer recurrence. Feelings of anxiety were also discussed in relation to a patient’s fear of an uncertain future, like fear of cancer recurrence however, the direction of this relationship is unclear. Anxiety was also related to certain aspects of functional impairment such as sexual dysfunction which can impact on sexual activity, and the experience of pain and fatigue which could lead patients to believe that they were not recovering from cancer.

Another objective of this thesis was to explore what could limit the experience of future disorientation. Functional social support (Bloom & Spiegel, 1984; Bloom et al, 2001; Michael et al, 2002) and positive coping strategies (Llewellyn et al, 2007; Llewellyn et al, 2008; Tix & Fraser 1998) were identified in the literature review as factors which could potentially limit the consequences of future disorientation; while the opposite were identified as potentially contributing to the experience of future disorientation (negative coping strategies and a lack of functional support). The evidence presented in this thesis supports the idea that functional support can limit the impact of future disorientation as those participants who felt that they had adequate support from their partners, friends and/or family seemed to experience a reduction in the consequences of future disorientation over time. However, those patients who felt that they did not have adequate support tended to experience a continuation of the consequences of future disorientation over time. The role of functional support seemed to reduce the impact of all of the consequences of future disorientation indicating that it may be an important area to study in the future. To aid the flow of the conceptual framework, a lack of functional support was included as potentially contributing to disrupted views of the future.

Finally, the data that emerged from the interviews with participants also seemed to support the assertion that positive coping strategies may be able to reduce the impact of consequences of future disorientation. Patients who adopted positive coping strategies such as problem focussed coping or acceptance experienced a reduction in the consequences of future disorientation over the course of the two interviews. Similar to functional support, this was the case for all three identified consequences of future disorientation. Also those patients who used negative coping strategies such as avoidance or emotional suppression seemed to encounter a continuation of the consequences of future disorientation across both interviews. This suggests that using negative coping strategies

may contribute to, and prolong the experience of, future disorientation and therefore this was also included in the top strand of the framework.

In summary the results of this thesis have culminated in the creation of the above conceptual framework which seeks to represent the experience of future disorientation in adults living with and beyond cancer for the participants in this study. This framework could be used to develop a quantitative measure of future disorientation which can then be used to assess the prevalence of future disorientation in a larger sample of people living with and beyond cancer.

#### **8.4 Strengths and limitations of this study**

I feel that one of the main strengths of this study is the commitment made to illuminating the experience of men and women who are living with and beyond cancer. This is something which had been lacking in previous literature on future disorientation which focussed only on the experience of women. This commitment is demonstrated firstly by adopting a qualitative approach which allowed me to gain a deep understanding of the participants' lived experience. The decision to adopt a qualitative approach to this research was borne out of my review of the literature which highlighted that few studies had explored the experience of future disorientation in women. Therefore I felt that a theoretical framework of future disorientation was needed, and in order to develop this framework a qualitative approach was used as this allowed me to illicit the real life experience of future disorientation, what may cause it and what may limit its effects. I decided that the best way to achieve this was through the use of semi-structured interviews as while this involved using an interview schedule covering broad topics to be discussed, it allowed for me to probe areas of a patient's life that may be related to future disorientation that I had not considered.

A further strength of this study was my decision to interview participants on two separate occasions, further highlighting my commitment to illuminating their experience as it allowed me to look at the long term impact of future disorientation. The second interview also presented an opportunity to probe issues that had arisen in the first interview that had perhaps been missed but had been identified during the analysis process for the first interviews as an area that should be explored further. An additional strength of this study was the high retention rate of participants, with only one participant out of the eight recruited not completing the second interview. This demonstrated that the participants were happy to discuss their experiences with me and allowed me to garner a detailed account of the experience of future disorientation over time.

The chosen methodology for this particular research also reflects the commitment I made to explore the lived experience of future disorientation of my participants; IPA is an idiographic methodology with its roots in hermeneutics and phenomenology (Smith, J. A. et al, 2009). The main goal of IPA research is to attempt to make sense of a participant attempting to make sense of their experience of a major life event. Therefore at the heart of IPA is a commitment to reflect the experience of an individual, and while these individual accounts can be used to build up a more general account of an experience, this is always with reference to the individual accounts of the participants. The interview schedule was deliberately kept open in line with an idiographic approach as each participant's experience is seen as unique then the use of very focussed questions on what I felt constituted future disorientation would be inappropriate. This is reflected in the very first question asked of each participant 'Can you please talk me through your cancer journey?' It may seem peculiar that in a thesis aiming to develop a conceptual framework of future disorientation that the first question on the interview schedule should direct participant's focus to the past. However, the decision to ask this question first was taken

for a number of reasons. Firstly it was designed to get the participants comfortable talking to me, as cancer has been a part of the majority of the participants' lives for a number of years then it was likely that they would have a lot to say about their cancer journey. Secondly as one of the strands of the conceptual framework is focussing on what may contribute to the experience of future disorientation then it was hoped that this question would uncover some of the underlying consequences of their cancer diagnosis and treatment which may be involved in the development of future disorientation. Finally as IPA studies focus on the lived experience of individuals then I felt that it was fundamental to open the interview with a question that focussed on the lived experience of the participants.

While I feel that the present study has a number of strengths, I feel at this point it is appropriate to highlight some limitations of this study which could be addressed with future research. I had a number of issues around the recruitment of participants to this study which I feel were limitations. Firstly as I used gatekeepers to make initial contact with patients I am unaware of how many patients were asked to participate and therefore do not have any concept of how many patients declined to participate. In future I would ask any gatekeepers who agree to approach potential participants for me to make a note of how many people they approach to take part in the study. Furthermore, after making initial contact with gatekeepers who agreed to recruit participants to the study, a long period of time passed with no invitation letters being returned. Therefore I took the decision, on the advice of supervisors to ask to attend a meeting of the CNS in oncology where I gave a short presentation on my research and outlined the minimal role required of them. After this I began to receive signed invitation letters from patients which allowed me to contact them to arrange interviews.

However, once I began to recruit participants it became apparent that the majority of them were coming from the colorectal cancer CNS. This highlighted another potential limitation of this study, the sampling framework. The sampling framework was left as open as possible so that any CNS could refer patients with various forms of cancer. This was to allow for a fuller understanding of future disorientation to develop. However in reality only two CNS ever made contact to say they had interested participants. This resulted in six participants with colorectal cancer being recruited and two with gynaecological cancer. While I feel that the sample I have recruited is sufficient to answer my research aims and have provided me with sufficient data to develop the conceptual framework this experience has taught me that perhaps a more detailed sampling framework would have provided a more representative sample.

While the sample size for this study is in line with the recommendations for IPA research at PhD level of between four and ten participants (Smith, J. A. et al, 2009 p. 52) the sample size could be considered quite small. This makes generalisation of the experience of future disorientation to all adults living with and beyond cancer difficult. However, it could be counter argued that the purpose of an IPA study is not to gain a general picture of a phenomenon but rather to explore individual experiences. While we can gain a general understanding of what an experience is like for this particular group of participants through consensus between the individual accounts, these results do not profess to offer an overall understanding of future disorientation in adults living with and beyond cancer. What these results do provide however is the basis for a conceptual framework which could be tested on a much larger sample size in the future.

It could also be argued that the use of IPA as a methodology raises issues around the validity of the results. While I had a supervision team who were involved in the analysis process to some extent, the data provided in the results chapters are my interpretations of



the participant trying to make sense of their experience and are not the results of a collaborative analytical process. However, as discussed in more detail in Chapter 4.7, it would be a redundant process to involve more than one researcher in the analysis process of the results presented would then become another researchers attempt to make sense of my attempt to make sense of the participant's experience. It is possible for multiple researchers to undertake an IPA study together. For example different researchers could analyse separate transcripts and then collaborate on the organisation of super-ordinate themes and sub-themes rather than all analysing the same transcripts and then trying to reach consensus about what the participant is trying to say about their experience. For obvious reasons this would not be an appropriate method of analysis for an IPA PhD research project.

In summary, I feel that the results presented in this thesis represent the real life experience of future disorientation in adults who have finished treatment for cancer. All of the participants recruited for this study have been diagnosed with cancer and had finished their primary treatment at the time of the first interview. The length of time since finishing treatment from cancer varied from between six months and four years therefore illuminates the experience of future disorientation at different points in the cancer journey. Furthermore by recruiting both men and women to this study it allowed for the exploration of the lived experience of future disorientation in men, something which has not been investigated previously. I feel that the use of semi-structured interviews was vital to gaining an insight into the patients experience and developing the conceptual framework. The use of a pre-prepared interview schedule meant that I could probe certain areas of the patient experience which may relate to future disorientation which had been identified in the literature review chapter (Chapter 2) and also allowed me to probe areas of interest that came up in the interviews that had not been anticipated. Having discussed the strengths

and weaknesses of this thesis I will now move on to summarise the main findings of this thesis in relation to the wider literature.

### **8.5 Conclusion and future areas of research**

In conclusion, this research used a longitudinal qualitative approach utilising IPA to illuminate the experience of future disorientation in adults living with and beyond colorectal and gynaecological cancer. This approach allowed for the development of a conceptual framework which consists of factors which contribute to the experience of future disorientation, factors which can reduce its impact and what the consequences of future disorientation can be. While it is felt that the results presented in this thesis provide a detailed account of the experience of future disorientation amongst those participants who took part in this study, a number of areas have been identified where research should be conducted in the future.

Firstly this research built on the work of Maughan and Clarke, C. L. (2001) and Roberts and Clarke, C. L. (2009) who identified that future disorientation could lead to an inability to come to terms with not being able to have children following a hysterectomy. While none of the men in this study suffered future disorientation due to the impact of infertility, this research has highlighted that it is a distinct possibility. Erectile dysfunction and gonadectomy are potential consequences of cancer treatment for men (Winstanley, Gust, & Strathee, 2004) and this could result in the experience of future disorientation if they have not had children, or all of the children they had planned. Future research into the experience of future disorientation in men living with and beyond testicular cancer in particular may be useful in exploring this possibility.

Secondly, this research highlighted that future disorientation has a number of consequences for the participants in this sample, such as being unable to plan for the future, and an

inability to return to full time employment. However, as this study was conducted with a relatively small number of participants, drawn from just two cancer groups there is a possibility that future disorientation can have other consequences which were not elucidated through this research. Therefore, further qualitative research may be required with patients with various tumour locations in order to explore this phenomenon fully.

Finally, this research has highlighted that functional support provided by friends and family, and the use of positive coping strategies has the potential to reduce the impact of future disorientation. Research in the future could focus specifically on reducing the impact of future disorientation to unpick which aspects of functional support, and what type of coping strategies are most effective at reducing its impact. This could then lead to the development of tailored interventions which could help people living with and beyond cancer to regain a sense of their future after treatment.

This research can be used to develop a quantitative measure of the experience of future disorientation amongst individuals diagnosed with cancer. As discussed in chapter 2, there are a number of consequences of cancer and its treatment which can persist for a long time after treatment such as financial concerns, psychological impacts, and sexual dysfunction which are not being addressed within the current follow up method. Furthermore, research has suggested that those individuals who see the same person for follow up appointments tend to adjust better to cancer. Therefore this research has implications for clinical practice as it would appear that any interventions designed to address future disorientation should be delivered by a clinician or clinical nurse specialist who has regular contact with patients. These interventions should be aimed at reducing the consequences of cancer identified in this thesis which can lead to future disorientation such as; sexual dysfunction, occupational concerns, anxiety, fear of recurrence and the physical consequences of cancer and its treatment. Furthermore, future disorientation is potentially something which can be

experienced in other clinical populations, the literature review has highlighted that patients who suffer a stroke may also be susceptible to future disorientation as they are psychologically unprepared for their illness, suffer from fears of recurrence and may be living with an uncertain future. Therefore, future research should aim to expand research into future disorientation for other illnesses such as cancer that have long-term consequences after the acute phase of the illness.

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## Appendices

### Appendix A – Participant Consent Form

Centre Number: 1

Study Number: 2

Patient Identification Number for this study:

#### CONSENT FORM

##### **Exploring the Relationship Between Psychological Well-Being and Future Disorientation in Cancer Survivors**

Name of Researcher: Mr Grant McGeechan

I confirm that I have read and understand the information sheet dated ... 2011 ☐ •  
for the above study.

I have had the opportunity to consider the information, ask questions and have ☐  
had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw ☐ •  
at any time, without giving any reason, without my medical care or legal  
rights being affected.

I understand that if I withdraw from the study any information collected up to ☐  
that point will still be used

I agree that the interview will be audio recorded to allow for accurate ☐  
transcription after the interview.

I agree that direct quotes can be used in any publications resulting from this ☐  
study. Any quotes will be anonymous and not traceable back to me.

I understand that data collected during the study may be looked at by ☐  
individuals from regulatory authorities from the NHS Trust where it is  
relevant to my taking part in this research. I give permission for these  
individual to have access to this information

I agree to take part in the above research study. ☐ •

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Name of Patient

---

Date

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Signature

---

Researcher

Date

Signature

When complete, 1 copy for patient: 1 copy for researcher site file: 1 (original) to be kept in medical notes.

## Appendix B – Invitation Letter – Interview 1

Dear \_\_\_\_\_,

We are conducting research on the experiences of cancer survivors, and what impact their cancer diagnosis and treatment has had on their psychological well-being (general feelings of contentment at one's life). We are also interested in how cancer has affected your view of the future, and what relationship this may have with your psychological well-being. If a link is found then we hope to use this information to develop a tool for identifying patients who have ceased cancer treatment but may be at risk of poor psychological outcomes.

### **How could you take part?**

If you are interested in being involved in this research you will be invited to attend an interview with the chief investigator, where you will be asked questions relating to your experiences as someone who is no longer receiving primary treatment for cancer. Prior to the interview you will be provided with two short questionnaires which are currently used to assess psychological well-being in people who are no longer undergoing treatment for cancer. You are not required to fill these questionnaires in, but merely to read them over as they will be discussed during the interview to gain your views on them.

### **What to do if you are interested in taking part in this study?**

If you have decided that you do not wish to take part in this study then you do not need to do anything. I would like to thank you for taking the time to read this letter.

If you want to be involved in this research, please take time to read the **information sheet** which is included with this letter which will provide you with more information about this study. If you would like to take part please fill in the reply slip below and return it to your clinical nurse specialist. The reply slip will then be securely passed on to Grant McGeechan. If you need help to fill in the reply slip please contact us. When we receive the reply slip we will then contact you to arrange an interview.

Yours sincerely,

Grant McGeechan,  
Chief Investigator.

✂

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I would be interested in taking part in the study, and hereby give permission to be contacted by the research team. I understand that before taking part, I will need to fill in a consent form and that if I want to I can withdraw from the study at any time.

Name \_\_\_\_\_

Contact Number \_\_\_\_\_

Signature \_\_\_\_\_

Date \_\_\_\_\_

## Appendix C – Invitation Letter – Interview 2

Dear [insert name],

A few months ago you were invited to participate in research we are conducting on the experiences of cancer survivors, and what impact their cancer diagnosis and treatment has had on their psychological well-being (general feelings of contentment at one's life). We are also interested in how cancer has affected your view of the future, and what relationship this may have with your psychological well-being. At the time it was mentioned that we would contact you again to take part in a second interview to see what changes if any have taken place in your situation in the last 6 months.

### **How could you take part?**

The format will be exactly the same as before. If you are interested in being involved in this research you will be invited to attend an interview with the chief investigator, where you will be asked questions relating to your experiences as someone who is no longer receiving primary treatment for cancer. Prior to the interview you will be provided with two short questionnaires which are currently used to assess psychological well-being in people who are no longer undergoing treatment for cancer. You are not required to fill these questionnaires in, but merely to read them over as they will be discussed during the interview to gain your views on them.

### **What to do if you are interested in taking part in this study?**

If you wish to continue in this research, please take time to read the **information sheet** which is included with this letter which will provide you with more information about this study. If you would like to take part please fill in the reply slip below and return it to your clinical nurse specialist. The reply slip will then be securely passed on to Grant McGeechan. If you need help to fill in the reply slip please contact us. When we receive the reply slip we will then contact you to arrange another interview.

If you have decided that you do not wish to take part in this study then you do not need to do anything. I would like to thank you for taking the time to read this letter.

Yours sincerely,  
Grant McGeechan,  
Chief Investigator.

✂

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I would be interested in taking part in the study, and hereby give permission to be contacted by the research team. I understand that before taking part, I will need to fill in a consent form and that if I want to I can withdraw from the study at any time.

Name \_\_\_\_\_

Signature \_\_\_\_\_

Date \_\_\_\_\_

## Appendix D – Letter to GP informing them of participation



Dear Dr (name),

I am writing to you to inform you that your patient (insert name) has agreed to take part in a research study being conducted in conjunction with Northumbria University and Gateshead NHS Trust. The study is designed to assess Psychological Well-Being and a possible connection with disrupted views of one's future in cancer patients who are no longer undergoing treatment. I have included with this letter a copy of the patient information sheet which explains the study in more details. It should be noted that the study does not involve trial of any medication or invasive procedure but consists of an interview to gain an understanding of participant's experiences of cancer and completion of two questionnaires. If you have any questions about this study please feel free to contact me on the details below.

Yours sincerely,

Grant McGeechan,  
Chief Investigator,  
Room H005, Coach Lane Campus,  
Northumbria University,  
Grant.mcgeechan@northumbria.ac.uk

## **Appendix E – Participant Information Sheet**

### **What happens if I don't want to carry on with the study?**

You can withdraw from the study at any time until the start of data analysis without it having any affect on your clinical care but, with your permission, we will use any information collected up to that point.

### **Will my taking part in this study be kept confidential?**

All information that is collected about you during this research will be kept strictly confidential to the research team. People from Gateshead Health NHS Foundation Trust may look at the information to check that the study is being carried out correctly (Research Audit). All will have a duty of confidentiality to you as a research participant and nothing that could reveal your identity will be disclosed outside the research site. The researchers do have a responsibility to disclose certain facts to your consultant if they are relevant or a risk to your clinical management and care. Furthermore, due to the sensitive nature of the interviews, should you become distressed then the researcher may have to cease the interview and contact your key worker. These are the only circumstances in which confidentiality would be breached. All questionnaires will be anonymous (your name will be removed) and will be stored in a locked office, within the University of Northumbria. All participants will be given a coded number and the index will be kept in the researchers coding information file. Interviews will be audio taped to help to ensure accurate

records are maintained. The audio-recordings will be transcribed in full. All of the tapes and the paper transcripts will be stored in locked facilities and will be treated with the strictest confidentiality. All paper records will be shredded and tapes wiped clean once the final study report has been produced.

### **What will happen to the results of the research study?**

We will publish the results in local and national journals and we will send you a copy of the results. We also intend to speak about the findings at scientific meetings. You will not be identified in any report or publication, unless you have specifically consented to such information. All participants will be provided with a brief summary of the results at the end of the study.

### **Who has reviewed the study?**

This study has been reviewed and approved by the NRES Committee North East – County Durham & Tees Valley Research Ethics Committee and also an Ethics Committee at the University of Northumbria.

Thank you for taking time to read this information leaflet.

Contact Details: Grant McGeechan

Chief Investigator/PhD Student

**T:**07766223788 **E:**grant.mcgeechan@unn.ac.uk

## **Psychological well-being and future uncertainty after cancer treatment.**

## **Patient Information Sheet**



You are being invited to take part in a research study. Before you decide to be involved, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Please use the contact telephone number to contact one of the researchers if you need any further information or if something is not clear. Take time to decide whether or not you wish to take part.

### **What is the purpose of the study?**

This study is being carried out to explore a possible relationship between poor psychological health (psychological well-being), and worries about the future (future disorientation) experienced after treatment for cancer.

We want to look for a relationship between future disorientation and psychological well-being as if a relationship exists then it may be possible to identify service-users with potentially poor psychological health at an early stage.

### **Why have I been chosen?**

Your Consultant or Clinical Nurse Specialist have indicated that you have recently completed cancer treatment and may like to be involved in this study. We are interested in talking to people who have recently completed treatment for cancer about their experiences since they ceased treatment. We also want to know about their views of their future.

### **Do I have to take part?**

No. You are under no obligation to take part in this study. If you do, you will be given this information sheet to keep and asked to sign a consent form allowing us to contact you in the future. If you agree to take part in this study, but later decide that you would like to withdraw then you can do so without giving a reason, even if you have already completed the first stage of the study. Deciding not to take part in this study or withdrawing at any stage will **not** affect the care you receive.

### **What will happen to me if I take part?**

You will be contacted initially by one of the researchers. The purpose of the study will be explained to you. You will be asked to participate in a one-on-one interview with the chief investigator. Your GP will be informed if you agree to participate in the study. During the interview you will be asked questions about your experiences post cancer treatment and about your views of your future. Prior to the interview we will ask you to complete two short questionnaires which are designed to measure your psychological well-being. At the end of the study you will in all probability be asked if we can contact you in the future to take part in a second phase of this study, where will ask you to attend another interview.

### **I'm interested, but need to know exactly what I'm committing to.**

The entire interview will last for approximately one hour and will be conducted at Queen Elizabeth Hospital in Gateshead, or at a place of your convenience. Completion of the questionnaires should take

approximately 15-20 minutes. Should you agree to take part in the 2<sup>nd</sup> phase of the study, we will invite you to attend another interview 6 months later which will also last for approximately one hour.

### **What are the possible benefits of taking part?**

While we cannot promise that taking part in this study will benefit you directly, the information you provide may help improve the psychological well-being of patients after cancer treatment in the future.

### **What are the possible risks of taking part?**

The evaluation study consists only of the methods described above so there is no risk of any physical harm or discomfort to you. However, the interviews will be asking you to talk about your cancer and about your treatment, and this could be unsettling or upsetting for some people. We will do everything we can to minimize any distress but we cannot promise to avoid it completely.

### **What if there is a problem?**

In the extremely unlikely event that any harm should come to you whilst you are directly engaged in the study, indemnity insurance is provided by Gateshead Foundation NHS Trust which is the sponsor of the study. Any complaints about how you have been dealt with during the study or any possible harm you might suffer will be addressed. If you require assistance, the researcher will know who to put you in touch with, support groups etc., who can help you deal with any issues that might come to light during the questionnaire or interview. If you feel that you need to make a complaint regarding your participation in this study we

would ask you to contact us to discuss the issue. If you still feel that the issue still hasn't been addressed then we would advise you to follow the Trusts complaints procedure, details of which are below.

If you have any concerns about this study you are advised to contact the Patient Advisory Liaison Service (PALs)

**PALs desk**

Main Entrance

Queen Elizabeth Hospital

Sheriff Hill

Gateshead

NE9 6SX

Tel: 0191 445 6129

**Complaints Manager**

Hazel Rogerson

Gateshead Health NHS

Foundation Trust

Queen Elizabeth Hospital

Sheriff Hill

Gateshead

NE9 6SX

Tel: 0191 445 6047

Appendix F – The Warwick and Edinburgh Mental Well-being Scale

## The Warwick-Edinburgh Mental Well-being Scale (WEMWBS)

Below are some statements about feelings and thoughts.

Please tick the box that best describes your experience of each over the last 2 weeks

STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been feeling interested in other people	1	2	3	4	5
I've had energy to spare	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling good about myself	1	2	3	4	5
I've been feeling close to other people	1	2	3	4	5
I've been feeling confident	1	2	3	4	5
I've been able to make up my own mind about things	1	2	3	4	5
I've been feeling loved	1	2	3	4	5
I've been interested in new things	1	2	3	4	5
I've been feeling cheerful	1	2	3	4	5

Warwick-Edinburgh Mental Well-Being Scale (WEMWBS)

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## Appendix G – The Impact of Cancer Scale

### **Impact of Cancer Scale**

#### EMPLOYMENT

1. Are you fully retired from paid employment?

\_\_\_\_\_ 1 Yes *go to NEXT PAGE*

\_\_\_\_\_ 2 No

1. Were you employed and earning income at some time during the last 12 months?

\_\_\_\_\_ 1 Yes \_\_\_\_\_ 2 No *go to NEXT PAGE*

*Please circle the number for each statement below that best describes how much you agree or disagree with the statement.*

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Disagree
3	I am concerned about not being able to work if I were to become ill again.....	1	2	3	4	5
4	Concerns about losing health insurance keep me in the job I have now.....	1	2	3	4	5
5	I worry about being forced to retire or quit work before I am ready.....	1	2	3	4	5

*Continued on next page*

## LIFE OUTLOOK

We are interested in knowing about your personal views or perspectives on life. Given your life **as it is now**, how much do you agree or disagree with each of the following statements?

*Please circle the number for each statement that best describes how much you agree or disagree with the statement.*

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Disagree
1	Because of cancer I live each day one at a time.....	1	2	3	4	5
2	I feel grateful to be alive.....	1	2	3	4	5
3	I feel like time in my life is limited.....	1	2	3	4	5
4	I learned something about life because of having had cancer.....	1	2	3	4	5
5	Having had cancer makes me feel unsure about my future.....	1	2	3	4	5
6	I worry about my future.....	1	2	3	4	5
7	I am afraid to die.....	1	2	3	4	5
8	I can accept my mortality, that I am going to die someday.....	1	2	3	4	5
9	I feel like time in my life is running out...	1	2	3	4	5
10	Having had cancer has made me realise that time is precious.....	1	2	3	4	5
11	Having had cancer has strengthened my religious faith or my sense of spirituality	1	2	3	4	5

*Continued on next page*

## YOUR BODY AND YOUR HEALTH

We are interested to know how having had cancer **NOW** affects your body and your health, if at all.

*Please circle the number for each statement that best describes how much you agree or disagree with the statement.*

		<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Neutra 1</b>	<b>Agree</b>	<b>Strongly Disagree</b>
1	I do not take my body for granted since the cancer.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
2	Having had cancer has made me more concerned about my health.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
3	I am more aware of physical problems or changes in my body since the cancer.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
4	Other health problems not related to cancer bother me more than having had cancer.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
5	I worry about my health.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
6	I accept the changes my body has gone through as a result of cancer and its treatment.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
7	I worry about the cancer coming back or getting another cancer.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
8	New symptoms (aches, pains, getting sick, or the flu) make me worry about my cancer coming back.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
9	Having had cancer makes me feel uncertain about my health.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
10	I am concerned that my energy has not returned to what it was before I had cancer.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
11	I am bothered that my body cannot do what it could before I had cancer.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
12	I worry about how my body looks.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

*Please circle the number for each statement that best describes how much you agree or disagree with the statement.*

		<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Strongly Disagree</b>
13	I feel disfigured.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
14	I sometimes wear clothing to cover up parts of my body that I don't want others to see.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
15	Having had cancer has made me take better care of myself (my health).....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
16	Having to pay attention to my physical health interferes with my life.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
17	I am unable to think or remember things like I used to.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

*Continued on next page*

**FEELINGS ABOUT CANCER**

Given your life as it is NOW, how do you feel about having had cancer?

*Please circle the number for each statement that best describes how much you agree or disagree with the statement.*

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Disagree
1	I consider myself to be a cancer survivor..	1	2	3	4	5
2	I feel a sense of pride or accomplishment from surviving cancer..	1	2	3	4	5
3	I learned something about myself because of having had cancer.....	1	2	3	4	5
4	I am angry about having cancer.....	1	2	3	4	5
5	I feel guilty for somehow being responsible for my cancer.....	1	2	3	4	5
6	I feel that I am a role model to other people with cancer.....	1	2	3	4	5
7	As time goes on, having had cancer becomes less important to me.....	1	2	3	4	5
8	Having had cancer has made me feel old	1	2	3	4	5
9	I feel guilty today for not having been available for my family when I had cancer.....	1	2	3	4	5
10	My sense of myself as a cancer survivor has lessened over time.....	1	2	3	4	5
11	My life would be better today if I had not had cancer.....	1	2	3	4	5
12	Having had cancer has been the most difficult experience of my life.....	1	2	3	4	5

*Continued on next page*



*Please circle the number for each statement that best describes how much you agree or disagree with the statement.*

		<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Strongly Disagree</b>
13	Having had cancer has not been as big a deal as other things that have happened in my life.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
14	I view having had cancer as a private experience.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
15	I wish to forget about having had cancer	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
16	I am constantly reminded that I had cancer.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
17	Something good has come from having had cancer.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
18	I think the doctors should have done a better job treating my cancer.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
19	Now that my treatment has ended I feel like my cancer doctors are not interested in my well-being.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

*Continued on next page*

## MEANING OF CANCER

Given your life as it is now, how much do you agree or disagree with each of these statements about cancer?

*Please circle the number for each statement that best describes how much you agree or disagree with the statement.*

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Disagree
1	I wonder why I got cancer.....	1	2	3	4	5
2	It is important for me to know why I got cancer.....	1	2	3	4	5
3	Having had cancer turned into a reason to make changes in my life.....	1	2	3	4	5
4	Because of cancer I have become better about expressing what I want.....	1	2	3	4	5
5	Because of cancer I have more confidence in myself.....	1	2	3	4	5
6	Having had cancer has given me direction in life.....	1	2	3	4	5
7	I feel like cancer runs my life.....	1	2	3	4	5
8	Because of having had cancer I feel that I have more control of my life.....	1	2	3	4	5
9	I have financial problems that are related to having had cancer.....	1	2	3	4	5
10	<i>Question removed as related to health insurance which is irrelevant to our sample.</i>	1	2	3	4	5

*Continued on next page*

## ACTIVITIES AND RELATIONSHIPS

This section includes questions about your social activities and about important relationships in your life.

Given your life as it is now, how much do you agree or disagree with each of the following statements?

*(Circle the number for each statement that best describes how much you agree or disagree with the statement.)*

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Disagree
1	I place a higher value on my relationships with family or friends than I did before having had cancer.....	1	2	3	4	5
2	I feel a special bond with people with cancer.....	1	2	3	4	5
3	Because I had cancer I am more understanding of what other people may feel when they are seriously ill.....	1	2	3	4	5
4	Having had cancer has made me more willing to help others.....	1	2	3	4	5
5	I feel that I should give something back to others because I survived cancer.....	1	2	3	4	5
6	I worry about friends dying from cancer.	1	2	3	4	5
7	Having had cancer has made me feel alone.....	1	2	3	4	5
8	Having had cancer has made me feel like some people (friends, family, co-workers) do not understand me.....	1	2	3	4	5
9	I am concerned about my children getting cancer.....	1	2	3	4	5
10	Uncertainty about my future affects my decisions to make plans (examples: work, recreation/travel, get married, get involved in relationships, have a family, go to university).....	1	2	3	4	5
11	Having had cancer has motivated me to make plans for dying (get my affairs in order	1	2	3	4	5

*Continued on next page*

**Circle the number for each statement that best describes how much you agree or disagree with the statement.**

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Disagree
12	Having had cancer keeps me from doing activities I enjoy (example: travel, socialising, recreation, time with family)	1	2	3	4	5
13	On-going cancer-related or treatment-related symptoms (for example bladder or bowel control, lymphedema, hair loss, scars, infertility, menopause, lack of energy, impotence/sexual problems, aches, pain, or physical discomfort) interfere with my life.....	1	2	3	4	5

1. Are you currently married, living together as married, or in a significant relationship?

☐ 1 Yes    ~~Go to~~ **QUESTION 19 on NEXT PAGE**  
☐ 2 No  
                   ↓

Given your life as it is now, how much do you agree or disagree with each of the following statements?

**Please circle the number for each statement that best describes how much you agree or disagree with the statement.**

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Disagree
15	Uncertainties about my health or my future have made me delay getting married or getting involved in a serious relationship.....	1	2	3	4	5
16	I wonder how to tell a potential spouse, partner, boyfriend, or girlfriend that I have had cancer.....	1	2	3	4	5
17	I am concerned about how to tell a spouse, partner, boyfriend, or girlfriend that I may not be able to have children..	1	2	3	4	5
18	I worry about not having a spouse, partner, boyfriend, or girlfriend.....	1	2	3	4	5

**STOP HERE**

Please answer the following questions ONLY if you are **currently married, living together as married, or in a significant relationship. Otherwise, please stop.**

Given your life as it is now, how much do you agree or disagree with each of the following statements?

*Please circle the number for each statement that best describes how much you agree or disagree with the statement.*

		<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Strongly Disagree</b>
19	I am open and willing to discuss my cancer with my spouse/partner.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
20	My spouse/partner is open and willing to discuss my cancer with me.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
21	Uncertainty about my health has created problems in my relationship with my spouse/partner.....	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
22	I worry about my spouse/partner leaving me if I were to become ill again.	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

**STOP HERE**

## **Appendix H – Interview Schedule**

Prior to the interview, the following information will be given to participants:

- Why we are conducting the interview
- Why the participant has been asked to take part in this study
- Approximate length of the interview
- Reminded of their right to opt out at any time

### **Questions – Future Disorientation**

- Please could you talk about your cancer journey?
  - Type of cancer treatment, length of treatment
  - Impact on day to day life i.e. family life/impact on work life
  - Impact on social life/friends
- How did you feel when you were told you had come to the end of your cancer treatment?
  - Emotions felt?
- How would you describe your life at the moment?
- Can you tell me about the level of support you feel you have received since you finished treatment?
  - What kind of support have you received?
  - Familial/friends support
  - External support
- What does the future hold for you?
  - Can you make plans for the future?
  - More determined to carry out goals/dreams?
  - Is there anything you feel unable to do now?

### **Questions – Psychological Well-Being**

- Are these questionnaires relevant to your situation since you finished cancer treatment?
  - Was there anything you felt was particularly relevant/irrelevant?
  - Was there anything not covered by the questionnaires which you feel would be relevant?
- Do you have any difficult moments/days
  - How do you manage them? What helps?
- Has finishing treatment had an impact on your psychological well-being?
  - Do you feel better/worse now than you did while you were undergoing treatment?

## Appendix I – Interview transcript with initial Notes – Lucy Interview 2

Initial Notes	Interview with Lucy 2 -	Emergent Themes
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 – Getting along fine, pains 31 in her stomach and, 32 similar to symptoms 33 suffered with cervical 34 cancer. 35 36 37 38 Clinical support, told her 40 pains were nothing to worry 41 about. Got so bad they 42 eventually sent her for a 43 scan. 44 45 Fear of recurrence, lesions 46 and shadows showing up 47 on the scan 48  1 – Found tumour on the 2 pancreas 3	25/02/2013  I – Right ok so erm, this is just kinda going to be similar to the last time (L – right), erm same kinda questions just to see how things are progressing (I – mhmm), in the last 6 months, erm, same sort of things apply, if you want to stop at any time just let me know, (L – yeah) we can stop, everything like I say is anonymous, so your name will never be on anything, nothing should be traced back to you. And if you ever want to withdraw from the study at any point then you are still free to do so (L – okay). Okay erm so the first question is, if you can just talk me through the last 6 months, what's been happening?  L – Last 6 months? When, when, when, when did we see each other (I – we spoke in,...) in August wasn't it (I – think it was August, September time yeah) eh well since then everything, I mean, everything was sort of fine, hunky dory, but then about (pause) September time, I'd started getting these pains and things again, well the pains have never really gone away, me abdomen and stuff like that and they have just poo pooed it (I – mhmm) as adhesions and you know stuff like that erm and I saw Dr Smith (pause). Was it? In October (pause), about September/October time, I can't remember now erm and decided to send us for another scan (I – okay), and here, it was showing some lesions and shadows and stuff, er, me  lower kidney, me right kidney area, stomach, in between the stomach and the pancreas was a little sort of tumour. It wasn't Dr Smith sorry it was Dr Tyrrell (I –	

4		mhmm) who was his SHO at the
5		time. So obviously not the news I
6		wanted to hear, he erm decided
7	Clinical support – wasn't too	they would try us out... could do
8	worried about it, could	nothing, wait three month and
9	give her drugs to shrink the	have another scan, or they could
10	tumour and wait three	put me on a tablet called
11	months.	Tamoxafen which, has been sort
12		of shown in 30% of the cases to
13		reduce, or hold whatever's going
14		on (I – mhmm), so erm, we did
15		that eh, that was right, I had the
16	Decided to take drugs to	scan, I went back the week later,
17	reduce the tumour and go	sorry I'm, I'm jumbling stuff up
18	for another scan in 3 months	here (I – that's okay, take your
19		time) erm, and the, the results
20	Getting mixed up, difficult	weren't back because there was,
21	to recall?	you have to give it two weeks (I –
22		right) so I shouldn't have gone to
23	Mix up with appointment	the appointment but anyway,
24	shouldn't have gone to	because I was there he rang up
25	her follow up while they	and he got an interim report, and
26	were waiting on her scan	that was the report, and then he
27	results.	rang us a couple of days later,
28		after I'd started the Tamoxafen
29		and gave me a little bit more
30		detail and stuff like that, ahm and
31		interestingly enough me blood
32		markers had actually gone down
33		(I - right) even though I hadn't
34		started the Tamoxafen, you know
35		which was a bit strange. So the
36		plan was to, to, to sort of wait the
37		three month, erm and have a scan,
38		and see him again but, he wanted
39		to see us just before Christmas, so
40		went on the 20 <sup>th</sup> of December,
41		ahm, saw Dr Smith that time (I –
42		mhmm), he asked if I would try
43		and take the Tamoxafen, because
44		I'd had to split it, because I really
45		was struggling to take it, I was
46		
47	Side effects of treatment,	feeling sick, I was off me food, I
48	wasn't taking the Tamoxafen	was just, griping pains all the time
49	because it was making her	and stuff, I was just, didn't feel
50	feel ill, so started her on	well on it at all but obviously they
51	a lower dose	wanted us to carry on, so I said
		right and stated off... I now take
		it at night, and that seems to do
		the trick to a degree, erm that was
		the 20 <sup>th</sup> , went off to America to
		the dance competition, erm was
		very wary about going because
		obviously you know (I – yeah), I
		mean me insurance, technically
		would have been invalid but I
		haven't rang them and told them,
		so there you go (laughs) erm went
1		
2	Changed to taking medication	
3	at night and that seems to	
4	have made a difference	
5		
6		
7		



<p>8 9 – Plans, went to America 10 with her dancing group 11 12 Consequence of cancer, 13 didn't tell her insurance 14 company about recurrence 15 as it would have invalidated 16 her insurance 17 18 Side effects, feeling 19 lethargic 20 21 Source of anxiety, phoned 22 when she was in USA, and 23 asked her to come in the 24 next day which made her 25 think that it was something 26 seriously wrong. 27 28 29 30 31 32 33 34 Cancer on her mind, phone 35 call made it difficult for her 36 to enjoy her trip, she tried 37 to put the phone call to the 38 back of her mind. 39 40 41 42 43 44 Saw Dr as soon as she could 45 found fluid in the kidneys, 46 and her ureter was swollen 47 which mean that she would 48 need to have a stint put in 49 50 51</p> <p>1 2 3 4 Participant becomes upset 5 at the thought of having to 6 have another course of 7 chemotherapy, recalling 8 how difficult it was the last 9 time. 10 11</p>	<p>over there, and I was tired, but I you know, I did enjoy it, and I went to Graceland's, and the day I was due to dance, me mobile went, Dr Tyrrell (I – right), erm the results of the blood tests that they had done on the 20<sup>th</sup> had indicated that there was something wrong, erm with me kidney functioning, could I come to the clinic the next day, and I said, I don't think so, I'm in America (I – yeah), and he says 'oh sorry I forgot, you know don't worry'. I say's aye oh right, don't worry you know, ringing me in America, can you come the next day, just drink plenty of water, blah blah blah, so obviously that put a bit of a dampener on the rest of the time but I just tried to put it to the back of me mind (I – mhmm), got back on the 8<sup>th</sup> or something, 7<sup>th</sup>, 8<sup>th</sup>, saw him on the 10<sup>th</sup> ahm, went and had an ultra- scan done which, showed that the ureter and the kidney had fluid in it (I – mhmm) and the ureter was swollen, so they would refer us for eh and emergency erm urology appointment, so right, cause</p> <p>obviously the plan is if the Tamoxafen doesn't work )I – right), then it's looking at chemo again (I – mhmm). And the chemo that you have (participant becoming upset), or that I had, I think I hope it's not the same as they given us the last time, filters through the kidney, so they want the kidneys functioning, so anyway saw this consultant a week later, erm, Dr Singh, who basically wanted me in that day, and I went wow hang on here, you know this is just happening far too quick, you know, what's the urgency, and he had picked up that he thought that I was having chemo, and I says well that's news to me, if you know that, you know more than me, this is the plan, to go on to the Tamoxafen,</p>	
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<p>12 Clinical support, confusion  13 caused by seeing multiple  14 consultants who got mixed  15 up, led to confusion over  16 course of treatment.  17  18  19  20  21  22  23  24  25  26  27  28  29  30  31  32  33  34  35  36  37 Clinical support, Dr felt that  38 even if the scan showed  39 changes in the tumour he  40 feels it would still be too  41 early to worry.  42  43  44 Would wait another three  45 months before starting  46 chemo even if the markers  47 have gone up.  48  49  50 Had the shunt fitted to help  51 with the swollen ureter</p> <p>1  2  3 Side effects of treatment  4 stent irritates her bladder,  5 which was irritable to begin  6 with.  7  8 Downer – things starting to  9 get on top of her.  10  11 Thoughts on death, worried  12 that she won't be here at  13 Christmas.  14  15 Use of metaphors, light at</p>	<p>have a scan, see him again, which  I am seeing him on Fri...  Thursday, Dr Smith (I- mhmm),  erm and see if, you know, there's  been any changes or whether its  holding, or whatever, but Dr  Smith had even indicated when I  did see him, cause, that's been the  problem seeing Smith, Tyrrell,  Smith they're not quite on the  same (I – yeah), par, but Dr Smith  was saying he wouldn't be  bothered if even with this scan if  there was slight changes (I –  okay), eh and even if the markers  had gone up because it does take  time to work, he would do another  scan in another three months after  this and then obviously take it  from there, so that's what I am  hoping for (I – mhmm), but I've  just been absolutely... I went in,  literally three days later after I  saw Dr Singh, the urologist (I –  mhmm), and had the shunt put</p> <p>in, the stent, and that was a  nightmare and a half, erm, easy  operation, but it irritates your  bladder, well I've got an irritable  bladder to start with so, I was  literally running to the toilet every  two minutes and I got myself in a  right downer, I must admit I am  on a right downer at the minute,  erm can't see any light at the end  of the tunnel, just keep thinking  you know, am I going to be here  at Christmas, is this it this time,  you know, the thought of chemo,  is just something I really do not  wish to have to do again, erm you  know and it's hard, to keep myself  going and motivated, although  I'm still doing me keep fit classes,  I've pushed myself to go back, in  amongst that I've had the flu, this  bloody flu virus, I've got that, and  then to top it all, me older brother,  that lives in Sheffield died, got his  (I – sorry), funeral on Wednesday,  so it's been a hell of a, and in  amongst everything else, me  daughter Charlie, you know (I –  yeah I know Charlie yeah), she's</p>
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<p>16 the end of the tunnel.  17  18 Previous history of cancer,  19 can't face the thought of  20 having chemo again.  21  22 Forcing herself to keep busy  23 as if she was in the house  24 she would just dwell on  25 the cancer returning.  26  27 Things getting on top of her,  28 feeling down, ill, her brother  29 died and her daughter has  30 had irregular scans as well.  31  32  33  34  35  36  37  38  39  40  41  42  43  44  45  46 Things starting to get on top  47 of her, feels like she doesn't  48 want to carry on.  49  50  51</p> <p>1  2  3  4  5  6  7  8  9  10 Chemo was a horrible  11 experience, side effects  12 meant that she couldn't eat  13 made her ill for days on end  14  15 Dreaded the thought of her  16 next round of chemo  17 knowing how it would  18 make her feel.  19</p>	<p>had erm, abnormal smears, and as soon as we got back from America she had to go through to hospital and she's had to have erm, oh I'm forgetting what they call it, they've literally taking all of these cells off of the cervix, and sliced a bit off, a loop or something or other it's called, and thankfully everything else is fine with her (I – mhmm), but obviously we've had that scare as well so, it's been wonderful (laughs). So that, that's where I'm at.</p> <p>I – okay got a couple of questions just from what you've been saying there, erm</p> <p>(pause). So first thing you were saying there that if you did get the chemo again you hope that it wouldn't be the same as the last time, can you just explain a bit more what you mean, why...?</p> <p>L – Because it was horrible (I – yeah), absolutely horrible, erm, side effects for me where horrendous, it just felled me for four or five days, and okay that doesn't sound like a lot, but you, when you know you are going to have, that every three weeks, feeling nauseous, can't eat erm, cramps, I get leg cramps with it, to the point where I don't know where I want to be and, I do I agitate meself (I – mhmm), erm and it's just horrendous, and the prospect of that, and you just feel so alone because there is nothing anybody can do for you (I – yeah), you know it's, it's just horrible and, to be honest, I mean from what Dr Smith said, I don't think it would be the same, because from what he said, it was because it's only been a year since I really finished that lot, that last lot of chemo, well a year and a half now nearly erm, I think he's probably got something else</p>	
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<p>20 Leads to anxiety over the  21 the thought of having more  22 chemo.  23  24 Feels lonely as no one  25 understand what you  26 are going through and no  27 one can make you feel  28 better.  29  30 Hoping that she will be on  31 a different form of chemo  32 if it comes to it.  33  34  35  36  37  38  39  40  41 Body image, thought of  42 losing her hair again is  43 causing her distress.  44  45  46  47  48  49  50  51</p> <p>1  2  3 Occupying herself  4 stops her from dwelling  5 on the cancer, why she  6 forces herself to keep  7 occupied.  8  9  10  11  12  13  14  15  16 – Aches and pains bring her  17 mind back to cancer. Feels  18 she is obsessed with her  19 bowel movements as  20 she is constantly trying to  21 get it right. Goes back to  22 last interview where she had  23 changed her diet to try</p>	<p>planned which might be better, it  might be worse, I don't know (I –  yeah). And the thought of losing  me hair <i>again</i> you know, for the  <i>third</i> time, you know, just not  very nice, not very nice at all (I –  no can't imagine it would be)</p> <p>I – Erm you were saying like, you  are feeling a bit down just now,  that you're not really in a good  place, is there anything that you  do that maybe sort of</p> <p>makes you feel a bit better?</p> <p>L – When I'm busy and I'm  occupied, I'm fine (I – yeah), erm  that's why I've pushed meslef to  go back to the, me keep fit classes  and me little working job and  things like that, it's when I've got  nothing to do and I'm sitting, erm,  I just focus in on (phnoe rings; I –  sorry) has that gone off? (I – it's  just a text, hope it's not turned the  actual recording off, no it's not  that's fine). I just erm focus in  on, I get windy pains here, I get  crampy pains here, I mean they've  said I can get pains from the stent,  I've had dodgy bowels since I had  the op anyway, and trying to get  the right is, I've become totally  obsessed, it's like the old  evolutional melancholia that they  used to diagnose in the mental  healh problems in older people, I  feel as though that's what I'm  bloody like you know, oh God  I'm just totally you know, but I  mean the flu didn't help, that  totally felled me and made me  think oh my God you know, I had  nothing, I had no energy for  nothing, I just feel blunt, I don't  get a... I used to get a buzz about  doing stuff you know, and I had a  high about everything and I don't  get that anymore, but then the side  effects of the Tamoxafen (I –  yeah), mood swings, depression,  you know and is it that that's, but</p>	
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<p>24 and control her bowels.  25  26  27  28  29  30  31  32 Flu compounded her feeling  33 down as she felt more  34 lethargic. Feeling down,  35 doesn't get the same buzz  36 out of doing things that she  37 used to.  38  39  40  41  42 Isn't sure whether it is her  43 cancer or the medication  44 she is on which is making  45 her feel low.  46  47 Metaphors linked to  48 fear of dying.  49  50  51</p> <p>1 Feels that this is the  2 beginning of the end.  3  4 Concern for others, doesn't  5 want her family to see her  6 going downhill  7  8  9 Patient becomes upset  10 thinking about putting her  11 family through her illness,  12 feels guilty?  13  14 Prefers talking about it helps  15 to clear her head, because  16 she feels that she can't  17 talk to her family about it.  18  19 Feels she has to put a brave  20 face on for her family. Easy  21 to talk to strangers who  22 have no emotional  23 attachment to her.  24  25  26 Anxious about her follow  27 up appointment, hoping</p>	<p>that doesn't help obviously  because that just takes you down  into that bloody dark hole where  you start thinking things like am I  going to be here (I – yeah), it's  frightening and what I don't want,  I mean if this is, you know the  beginning of the end,</p> <p>that's the way I'll describe it, erm,  the thought and prospect of just  going downhill, I really, oh I  couldn't, I don't know if I can  cope with that, and I don't know,  I don't want my family having to  cope with that either, does that  make sense? (I – yeah that  makes sense, yeah). I'm going to  get meself upset now, erm (I – we  can stop), naw you're fine (I –  you sure?) No you're fine, I am  better talking about it actually and  I did break down with me sister in  law the other week, I find I can't  do it with the kids (I – yeah)  because to me I've got to stay  strong because I know how upset  they will be, Eric, well I just think  we walk on egg shells with each  other, at the minute you know,  with it, so I don't know whether  to go to the doctors and say you  know, do I need to have  something, I think Thursday  either it will, if he give us you  know says oh, it's not doing too  bad we'll give it another three  month, that probably will be a big  weight off me shoulders, but if I  go and things have progressed,  because I still have all these achy  pains and twinges and to me in  my mind well something's going  on you know (I – yeah) but I  mean it could be, I get a lot of  wind, and I canny get rid of it and,  that is absolutely painful, you  know so, I just don't know really,  really don't know and I think  that's, that's the hard bit, I don't  know what I'm dealing with,  when you're like in a no man's  land, and, and I say I'm like on a  3 month contract at the minute,  I'm like you know, I've got three  month and then we'll see how it</p>	
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<p>28 that she is told just to leave 29 it for another three months. 30 31 Not expecting good news, 32 feels that the aches and 33 pains that she is feeling 34 means that something is 35 going on and the cancer has 36 progressed. 37 38 However, feels it may just 39 be bad wind which she 40 suffers from. 41 42 Feeling out of control, the 43 hardest thing for her is not 44 knowing what is going on. 45 46 Metaphor – no mans land 47 feels she is just in limbo 48 waiting for three months 49 before she knows what 50 she is dealing with. 51</p> <p>1 Tries to just get on with life 2 and not think about it, but 3 she isn't getting the same 4 enjoyment out of life as she 5 was before. 6 7 Lethargy, by 9 at night she 8 feels completely done in, 9 which is not like her. 10 11 12 13 14 Feels the anxiety is to blame, 15 constantly worrying is 16 tiring her out. 17 18 19 20 21 22 23 24 25 26 27 28 Doesn't like taking 29 taking herbal remedies 30 which she feels will 31 boost her immune system</p>	<p>goes and you're trying to think well three moth,</p> <p>okay just get on with stuff, and I do try me best and I do get enjoyment out of things to a certain extent, I'm not sort of, down to that depth where nothing is a pleasure, but by 9 o'clock at night I am absolutely shattered (I – yeah), I'm worn out, I'm in bed you know, I want to be in bed by ten, or I'll sit here and I'll fall asleep, you know and that isn't me (I – yeah), you know erm and I know part of it is anxiety, that's the big thing as well, that doesn't help, I'm me own worst enemy, think I said that to you before didn't I.</p> <p>I – I think you did yeah erm how are you with the taking the Tamoxafen, because (L – how am I with the what?) Taking the Tamoxafen, cause I know you said the last time you don't like taking medication?</p> <p>L – I don't I mean taking, I've actually started taking some herbal remedies as well to try and boost me immune system erm I take it before I go to bed, so that id, and I'm, I've got a horrible taste in me mouth, I don't know if that's still the residue from the flu but I've had this beforehand, erm, side effects of sort of kidney dysfunction can be you can get a horrible taste although they said that mine was very mild in comparison (I – yeah) you know in comparison to the scheme of things, I still haven't, I had stopped smoking again and then this happened so I'm back on the fags, again! You know and I battle with meself everyday about that because I know I'm not doing meself any favours and I keep seeing this</p>	
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33		
34 Making sense of her		
35 symptoms – taste in her		
36 mouth is either the flu, or		
37 a symptom of her kidney		
38 dysfunction		
39		
40		
41		
42		
43		
44		
45 Health – started smoking		
46 again in response to her		
47 diagnosis. Feels this will		
48 help with her anxiety.		
49		
50		
51		
1 Preoccupation - notices		
2 adverts about cancer on the		
3 TV and the radio, cancer on		
4 her mind.		
5		
6		
7		
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10		
11 Feels she is tolerating the		
12 Tamoxafen, feels that is		
13 causing her upset stomach.		
14		
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19 Clinical support, putting		
20 things in perspective, the		
21 thought that there are		
22 people worse off than her		
23 doesn't make her feel any		
24 better about her own		
25 situation.		
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bloody advert on the television about it (I – mhmm), and every other advert seems to be you know people with cancer and you put the radio on and you know if you see blood in your pee and blah blah, and I think for God sake man will you go away, can I not just have a couple of days, but anyway we get back to the Tamoxafen (laughs), I'm tolerating it (I – yeah), whether that's still part and parcel of the ab... upset stomach and that I have no idea, Dr Smith doesn't seem to think so you know at the end of the day and Dr Tyrrell basically said there were people a lot worse off than me (I – mhmm), you know and in the scheme of things, yes (I – yeah) but it still doesn't make me, things nice for yourself you know (I – no I can't imagine it does).

I – How did you deal with it when they phoned and they said that they wanted to, to see you the next day, I mean how did that make you feel?

L – Well, when I was in America? (I – ahuh), erm well panicked you know, felt anxiety, felt the pit in me stomach straight away and then of course he's explaining it and I'm thinking right okay, you know, oh why the urgency then if it's alright then so you know you start thinking the worst case scenario, you know, Christ me kidney's packing in now, is it in me kidneys, and of course there is a suspicious area at the bottom so it could well be the lymph glands, you know, I don't know, there is too many unanswered questions for me

at the minute. (Phone rings) oh for god sake (I – that's okay I will

<p>36 Feeling of panic – the fact  37 that they wanted to see her  38 straight away made her  39 think that they had found  40 something serious,  41 otherwise why would there  42 be such urgency.  43  44 Thoughts on dying, felt  45 that her kidney was packing  46 in.  47  48  49  50 Control/info seeking, too  51 many unanswered questions</p> <p>1  2  3  4  5  6  7  8  9  10  11 As soon as dr says don't  12 worry, that is all she can do.  13  14 Tried to put things to the  15 back of her mind during her  16 dance competition but  17 admits that it kept coming  18 back to her. Couldn't  19 enjoy herself as she knew  20 what was awaiting her when  21 she came back to England.  22  23  24 Tried to think along the lines  25 off there is nothing I can do  26 about it. Felt that it did  27 affect her though, due to  28 lethargy  29  30  31  32  33  34 Didn't engage with the trip  35 as well as she would have  36 normally, went to bed early  37 only had a few drinks, would  38 usually be much more lively  39</p>	<p>just pause this) [RECORDING  PAUSES]</p> <p>[RESUMES]</p> <p>L – Oh dear me, so (I – where  were we?) About the Tamoxafen,  and how (I – yeah, yeah), did feel  eh well you know he's saying  don't worry and it's easier said  than done, and the irony of that  was it was on the day I was due to  dance, me competition dances  erm I mean I did actually put it in  the back of me mind, well there  isn't anything I can do but it did  you know, the thoughts did keep  coming back, oh God I've got to  go back to get that sorted out and  stuff and I thought oh well there  isn't anything I can do about it  but, I think either unconsciously it  probably affected me because  after that I was even more tired  and I didn't have life and bump  about me to enjoy the whole  experience like everybody else  was, I was away to bed at 10  o'clock (I – yeah), you know  which is, I mean I still had a few  drinks and stuff, but, nut couldn't  get enthused about anything, in  fact I find everything about life  negative, that's all I seem to do  (laughs), winge about stuff. (I –  did you dance at the  competition?) I did aye, I mean  there was 29 of us and I was 23<sup>rd</sup>  so at the end of the day I did me  best, I did enjoy it, I know so, at  erm, I didn't, I knew from the  start that I wasn't in with a chance  of winning anything, I just  wanted to go out there and  perform to the best of my ability  which I did do, because I'm not  going back to America, I had  already</p> <p>said that anyway (I – yeah) before  all of this kicked off, erm it's just  I can't afford it, it's too  expensive.</p> <p>I – erm just one of the things that</p>
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40 Still danced at the	I picked up on the last time that	
41 competition even though	we spoke about was that you said	
42 she didn't feel energetic.	that you weren't religious but you	
43	said that a lot of the time when	
44	you went to bed at night you	
45	would say the Lord's prayer and	
46	stuff, do you still...	
47		
48		
49		
50 Future – not going back to	L – I still do that not as often but I	
51 America – too expensive	still do cause I've, I've thought,	
	well what's the point erm (lauhgs)	
	cause it hasn't worked, oh dear,	
	erm. (I – why is it that you say	
	the prayer then if you don't find	
	yourself religious, why do you	
	find yourself saying it then?) I	
1	think because I need hope, I need	
2	hope of some description from	
3	somewhere and at the moment I	
4	don't feel that anybody is giving	
5	me any hope do you know what I	
6	mean, until I see Dr Smith on	
7	Thursday, and well, see what he's	
8	got to say he's, he's not the	
9	warmest of men, erm, but I mean	
10	it might not be him I see it might	
11	be bleeding Mansey again, I don't	
12	know, although I do believe	
13	Mansey might have gone, erm,	
14	but I'm assuming it's Dr Smith	
15	I'm going to see (pause).	
16		
17 Religion – isn't religious		
18 but felt that praying would	I – Erm the last time you spoke a	
19 protect her and give her	lot about dark clouds, like when	
20 the hope she needs that	eh you're going to bed at night,	
21 she isn't getting from	and you know is the last time I am	
22 elsewhere	going to go to bed, am I going to	
23	wake up tomorrow, is that, I	
24	imagine because of what's being	
25	going on that might be something	
26	that's still happening, do you	
27		
28		
29		
30		
31		
32 Clinical support, not sure	still feel that way at times, or is it	
33 which consultant she	not as bad now?	
34 will see.		
35		
36	L – Now I'm (pause), I don't	
37	know in a, in a, it's, it's a strange,	
38	it's sort of thing that I, I think, I	
39	hope I don't wake up tomorrow	
40	because I don't want to carry on	
41	with this (I – right), torments,	
42	that's what it feels like to me and,	
43	but then when I do wake up you	

44		know I'm fine about that erm and
45		I don't get upset about that
46		thought, I know that sounds
47		strange, it's like I've resigned
48		meself to the fact that I am going to
49		die (I – okay), the only question is
50		when (I – would, why, why do
51		you think you feel that way now?)
		Pffft (pause), I have no idea to be
		honest with you, erm, I think
		because I haven't got, I haven't
		got the hope, I haven't got the
		knowledge, I don't know what the
		plan is because sort of, seeing two
1		different consultants, I think
2		didn't help matters, yeah the plan
3		will be to do chemo but when I
4	Thoughts of dying have been	think about those things it's as
5	reinforced by her recent	though they haven't given up on
6	results however, the fear	me, it's like I've given up on
7	of dying isn't the same, she	meself, I think, and I've always
8	feels like she doesn't want to	maintained, I've always said I'd
9	carry on anymore and	rather have quality than have
10	actually hopes sometimes	quantity (I – yeah), erm, and
11	that she doesn't wake up.	maybe in my own mind I'm
12		making that decision
13		unconsciously that I'm not going
14	Thoughts on dying, resigned	to have the chemo, I don't know, I
15	herself to the fact that she	don't know, I just know that, I
16	is going to die.	cannot forsee myself for the rest
17		of my days, however long that
18		might be, going through what I
19		call purgatory (I – mmmm), cause
20		that's what chemo is, I don't care
21		what anyone says, I would rather
22	She feels she is going to die	be here on a bit of morphine and
23	because she doesn't have	feeling quite
24	that hope.	
25		
26	Uncertainly has also led	
27	to this resignation, would	
28	rather just see the one	
29	consultant. She feels that	
30	she has given up on herself	euphoric and you know, pain free,
31	goes back to her wanting	alright might not be able to do
32	quality of life, and her	much, but I would rather be like
33	uneasiness about having	that than lying curled up, feeling
34	chemo.	sick, not even being able to enjoy
35		food and you, you know enjoy life
36		(I – yeah) that I have so I don't
37		know maybe I'm consciously I've
38		already made that decision I don't
39		know but, again it depends what
40		happens on Thursday. I've
41		already told meself that I will give
42	Feels that is this is it this	the chemo one more go (I –
43	time then she doesn't want	mmmm), erm, depending on what
44	to have the chemo as she	it is, if it's the same as the last
45	doesn't want to spend the	time I think I might be having
46	rest of the time she has	words with them and saying, na I
47	feeling like crap.	don't kna, to me it obviously

48		didn't work last time, what makes
49		you think it's gonna work this time
50		(I – mmmm). So... I think, I don't
51		know (I – yeah), yeah (I – do you
		still get, well I don't know if it's
		still but erm, how do you feel
		before appointments, if you've
		got an appointment coming up
		how do you feel?) Oh I'm up a
		height already about Thursday (I
1		– yeah?) Dreading it, but of
2	Wants to enjoy life and not	course I've got a funeral on
3	spend her time feeling ill	Wednesday to go to which isn't
4	all of the time.	going to help matters either (I –
5		mmm), erm you know that's
6		going to be sad, I mean my
7		brother and I weren't close, erm
8		he is a half-brother, and he lived
9		down in Sheffield where me
10		mother was from so you know,
11		basically you know, but I'll go
12		down pay me respects, cause at
13	Contradiction, no chemo to	the end of the day you know (I –
14	will give it one more try.	yeah), I mean he was 82 so you
15		know, he's not a spring chicken (I
16	Resignation – it didn't work	– yeah) but nat.
17	the last time so what makes	
18	them think it will work this	
19	time.	
20		I – Erm you said as well the last
21		time that you get sort of agitated,
22		that you are pacing up
23		
24		
25		
26		
27		
28		
29		and down, you are chain smoking,
30	dreads follow up	drinking lots of coffee, is that the
31	appointments as she worries	same this time, yeah?
32	what they are going to tell	
33	her. Especially dreading	
34	this appointment as they	
35	have already found	L – It's about, it's about the same
36	something, and with	as I say I think erm there's times I
37	everything that has been	don't know where I want to be (I
38	going on.	– mmmm), but because I feel
39		tired, I usually end up lying
40		down (I – yeah), but there times
41		I'll lie down and I don't want to
42		lie down, and I'll get back up
43		again and you know, I potter
44		around here, but if I've got stuff
45		to do erm (I – yeah) things to be
46		thinking about like I'm doing me
47		voluntary work again this
48		afternoon in the school at 1
49		o'clock, so it's dentist at 12, into
50		the school at 1 (laughs), erm you
51		know, and yet I can still laugh (I –

<p>1</p> <p>2</p> <p>3</p> <p>4</p> <p>5</p> <p>6 Coping with anxiety, hasn't</p> <p>7 progressed over the last</p> <p>8 6 months as she feels she</p> <p>9 still she drinks too much</p> <p>10 coffee and smokes too much,</p> <p>11 also contributes to her</p> <p>12 lethargy and causes her</p> <p>13 to need to lie down in the</p> <p>14 afternoon.</p> <p>15</p> <p>16 Again fees that taking her</p> <p>17 mind off of things helps to</p> <p>18 deal with her anxiety</p> <p>19</p> <p>20</p> <p>21</p> <p>22</p> <p>23</p> <p>24</p> <p>25</p> <p>26 Loss of control - uncertainty</p> <p>27 causing her anxiety</p> <p>28</p> <p>29</p> <p>30</p> <p>31 Wants to know what is going</p> <p>32 on but also feels that she is</p> <p>33 perhaps better off not</p> <p>34 knowing, turmoil</p> <p>35 contributes to her anxiety.</p> <p>36</p> <p>37</p> <p>38</p> <p>39</p> <p>40</p> <p>41 Stopped seeking out</p> <p>42 information on her own as</p> <p>43 it doesn't help her, makes</p> <p>44 her feel worse.</p> <p>45</p> <p>46</p> <p>47</p> <p>48</p> <p>49</p> <p>50</p> <p>51</p>	<p>yeah) I do still have a bit of a sense of humour and I do get fleeting moments, as I say it's just I've got no control over any of this Grant and I think that's the problem, I'm such a control freak, that I need to know, but there's half of us is thinking, ignorance sometimes is bliss, you know if you don't know then you don't worry about it (I – mmmm) you know so, I'm just in turmoil with meself as usual. (I – so how do you balance that need to know, with the not wanting to know?) Well one of the things I've stopped meself doing is going on there (laptop) and researching stuff because that just, that peow, just sets me off, erm I mean I will ask questions, Dr Tyrrell said that to me, he says by you ask a lot of questions, and I said well I, I, I do need to know (I – mmmm) you know I asked him outright if he thought it was cancer in</p> <p>the, the kidney, cause I'm thinking along the lines of right, well you know, I can live with one kidney, they can take it out, and then of course this little tumour beside me pancreas and I'm thinking oh Christ, you know there's not many folk who survive pancreatic cancer, but if you catch it early enough they can take that away, they can take half me liver away, they can even take me stomach away you know and I can live with one lung, so I'm thinking, well there'll not be much of us left but (laughs). Oh dear, you have to laugh sometimes, but yeah, and I've lost the question, it's gone, that's the other thing me... (I - Oh yeah that's right I asked you how you balance like the needing to know with the not wanting to know?) Well, pft, I'll ask the questions I want to ask I think, and sometimes I'll hear the answers I don't want to hear (I – yeah), you know which might then, instigate me asking more questions, I don't know, at the end of the day see</p>	
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<p>1 2 3 Feels that once she knows 4 what she is dealing with then 5 she can handle it better and 6 move on. 7 8 Making sense of symptoms, 9 planning how she would deal 10 with a negative prognosis, 11 and seeing positives in that 12 she could survive with 13 cancer in certain areas. 14 15 16 17 18 19 20 21 22 23 24 25 26 Info seeking, will ask 27 questions that she feels she 28 needs answered but 29 doesn't always get the 30 answer she wants. 31 32 33 34 Limbo – living day to day. 35 36 37 38 39 40 41 42 43 44 45 46 47 48 Support – her and her 49 partner avoid talking about 50 the cancer now 51</p> <p>1 2 Thinks her family are</p>	<p>how it goes (I – yeah). It's all I can do, day by day really.</p> <p>I – Okay, how do you feel about erm sort of family support, you mentioned it a bit earlier on, cause I know that the last time you felt that the support wasn't the same second time around as when you had the breast cancer, erm how are you finding the support now, like from the kids and from Eric?</p> <p>L – Well as I say there is this unspoken, sort of erm, (pause), atmosphere if you like (I – mhmm), not really talking</p> <p>about it, I mean I think they are dreading Thursday as much as I am erm, as I've said to you earlier, I'm more concerned about how they feel, about the situation, I feel guilty in a respect that I'm putting them through this again (I – okay), erm, you know and I don't want them to be having their last sort of memories of me if you like of going down hill, and you know not even being able to get into bed and, becoming incontinent and just becoming sick all the time, because that's how I envisage it, I don't know, again I'm just speculating, it doesn't always happen like that. But, but Eric is there and I can get a cuddle off of him if I want one, he doesn't say anything, he doesn't ask anything erm, he just when I was diagnosed again at the clinic, all he said was you're strong, you'll come through it, and I just thinking, I am strong to a point but even I have a point where I feel like I just want to crumble, I just want to go away into a corner and just crawl away, I mean I've got this so called MacMillan nurse Mel who suddenly appeared back on the scene again from Wansbeck, she's now working more hours so she attends the outpatient clinic (I –</p>	
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<p>3 dreading her follow up 4 appointment, but doesn't 5 know as no one is talking 6 about it. 7 8 Guilt, feels it is her fault that 9 she is going through this and 10 that she is putting her 11 family through it. 12 13 Doesn't want her family to 14 have to see her go downhill 15 16 That's how she sees cancer 17 progressing where she is ill 18 all of the time doesn't 19 want to become a 20 burden for her family. 21 22 Still feels that she has to 23 ask her family for support 24 rather than them offering 25 it to her. 26 27 28 29 Giving up, feels she is at 30 breaking point. 31 32 33 34 Clinical support, mcmillan 35 nurse hasn't been 36 supportive, feels she is 37 only there when there is bad 38 news to be given. 39 40 41 42 43 44 45 46 47 48 49 50 51</p> <p>1 2 3 4 5 6</p>	<p>right). And of course she was there at the first one, and she was there the day I got diagnosed with the ovarian cancer so what did I say 'what are you doing here?' And I immediately made the link (I – mhmm), she's here because there's something, and it wasn't till after we came out that she explained that she had, but she is about as much use as a chocolate fire guard,</p> <p>and she rang us just last week cause there is an ovarian cancer (I – mhmm), erm away day at the Thistle hotel on the 8<sup>th</sup> of March (I – oh right okay), which I had seen on Facebook, but she sent, she rang us to tell us about that and send us a flier, she knew nothing about me being in hospital and having the stent put in or anything like that, and in fact the previous time she rang, she had to ask, had to ask me what they were doing, she obviously wasn't listening (I –mhmm), and the day Charlie and I had to go to (hospital) for her smears and everything (I – yeah), she was on duty in the clinic, and she walked straight past me, you know she never, never acknowledged us (I – yeah), so I've got no faith in her at all. (I – yeah that's a bit strange), so, well you know.</p> <p>I – What about other support, I know erm... (L – me sister in law), yeah you said she was a big help the last time?</p> <p>L – She is, she is very blunt, and very straight to the point (I – mhmm), I mean, in a way, what I need, I just need somebody to vent to, I need somebody to get all these dark horrible thoughts out of my head, once they are out of my head and I verbalise them, they don't seem as significant, if</p>
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7		that makes sense (I – yeah), erm
8		and she'll always come back with
9	McMillan nurse, doesn't even	something, which I don't always
10	now when her appointments	need you know erm, like putting
11	are, feels she doesn't care	things into 'deal with it' you
12	about her. Also ignored her	know 'sort it out', 'if that's a
13	when she bumped into	problem, deal with it, sort it out,
14	her in a clinic.	it's pointless worrying about it,
15		what do you need to do to
16		
17		
18		
19		make it comfortable and then put
20		it away and move onto the next
21		thing' and I thought well it's
22		easier said than done, you know
23		erm, but yeah she's there I can
24		call on her at anytime really (I –
25		yeah), so at least I do have some
26		support (I – mmmm) yeah. That's
27		about it really (I – is there
28		anything you don't feel you can
29		talk to Eric, and Charlie and that)
30		yeah well I mean obviously the
31		inevitable isn't it, the thoughts in
32		my head you know will I be here
33	Gets support from her	at Christmas, they just don't want
34	sister in law that she can't	to hear that, so I just don't talk to
35	get from anyone else, she is	them about that, but I mean
36	blunt and to the point, also	obviously if I get to the point
37	feels she can talk to her	where that's what I am told (I –
38	about death and dying, that	yeah) then we would all have to
39	she can't talk to her partner	sit and talk about it and again, I
40	or kids about. Sometimes,	would take control and whether,
41	she is too blunt though	they liked it or not I would
42		probably sit the three of them
43		down and say, right okay, this is it
44		you know, I don't want this and I
45		don't want that you know, really I
46		don't know if that's the right
47		thing to do, I don't know (I – if
48		it's right for you?) Well yeah at
49		the end of the day (I – yeah),
50		yeah, yeah you know, put the
51		affairs in order, I mean most of
		them are in order anyway, and I
		do occasionally say to them you
		know, I mean they'll say oh spend
		your money mam, but it's alright
		saying spend it, but there's
		nothing actually I want to spend
1		any of it on, there's nought I
2		really need so, what's the point in
3		wasting it (I – yeah), you know.
4		Erm the idea of going off away on
5		a holiday or anything like that, I
6	Feels her sister in law is	would be too worried I took ill
7	always there when she needs	when I was away, you know, not
8	her though.	that, I've got any indication that I
9		am going to take ill, you know it's
10		

<p>11 12 13 Doesn't want to talk to her 14 family about her thoughts 15 that she is going to die, 16 however depending on her 17 next follow up, she might 18 not have a choice but to 19 sit them down and talk to 20 them about it. 21 22 23 Takes control, would talk 24 to them on her terms, when 25 she feels ready. 26 27 28 29 30 31 32 Thoughts on death, already 33 has a lot of her affairs in 34 order. 35 36 Plans for future, kids tell 37 her not to worry about her 38 and spend her money, but 39 there isn't anything she 40 wants to spend her money 41 on. Feels like spending the 42 money on herself would be 43 a waste as she wouldn't 44 enjoy it. 45 46 47 Future plans, doesn't want 48 to book a holiday as she 49 is worried that she will 50 be too ill to go away 51</p> <p>1 2 Feeling deep down that her 3 time is up and nothing 4 she does seems to help. 5 6 7 Pains reinforce her idea that 8 something is wrong. 9 10 11 12 13 14</p>	<p>just this, this driving force or belief that I seem to have at the minute you know, that that's it, and it's hard to shift (I – mmmm), it really is hard to shift and rationalise, and challenge (I – yeah), you know so especially when I keep getting all of the pains, see that's just reinforcing the belief that I have that something is going on and things are progressing (I – yeah) you know quicker, the Tamoxafen isn't doing its job, you know, that's the belief I have.</p> <p>I – So I mean that's a change from the last time (L – oh aye), you still felt quite happy making plans, and the last time we spoke you were planning on going away to American and stuff, is it mostly the worry that you are going to be ill, or is it the, there any other reason why you think that you don't feel like making plans?</p> <p>L – Well I mean, I've got a, got a well I've got a holiday booked in August believe it or not to go to Greece, with the dance troupe, they are all going there, they have hired a villa, and I've paid me deposit and I am putting money away for that and, sort of in me mind thinking it would be nice sort of to go there but I know it will be a hot for us, and erm what I wouldn't do is go over there if I didn't feel well because what I wouldn't want to do is spoil everybody else's holiday by the fact that if I'm sitting there you know like, with no life and no energy, cause that's not me you know I'm usually one of the ones that will join in the fun and activity and stuff like that,</p>	
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31	Has a holiday booked for	
32	later in the year but if she	
33	is too ill at the time then	
34	she won't go as she doesn't	
35	want to ruin it for everybody	
36	else's.	
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48		
49	Change in personality,	
50	usually outgoing but feels	
51	more reserved these days.	
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2	Plans are revolving around	
3	her hospital appointments	
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19		the thought of wearing the bag,
20		it's more the sort of the feelings
21		associated with having one?) Oh
22		I wouldn't like to wear the bag
23		either cause then I couldn't,
24		there's sort of clothes you
25		couldn't wear and stuff like that,
26		I'd be conscious all the time of
27		you know was it filling up you
28		know and stuff like that, I, I,
29		certainly wouldn't like to have to
30		have one of those but, there again
31		the way I feel at the minute, if it's
32		in me bla, bowels and that's the
33	Didn't want a colostomy	option, well what else do I do?
34	bag as it would damage her	Do I go with that or not, I don't
35	self image which she feels	know? Everything at the minute
36	is low enough at the minute.	is just, I just feel as if I don't
37		know anything, (I – yeah) you
38		know that's the hard bit (I – do
39		you think it's that kind of
40	Bio disruption, when she	uncertainty that..?) Yeah, yeah
41	looks in the mirror she	that, that's it's like I say, if they
42	doesn't see herself	say to you right, you've got 6
43	looking back.	months, I know right fine, (laughs)
44		I'm not goan to be happy about it,
45		would be a total shock but I'd
46	Colostomy bag would make	know what I'm dealing with, it's
47	her feel unattractive, and	this, right we'll do another three
48	while she doesn't feel like	month, then we'll do another three
49	having sex at the minute	month, then you might have
50	that would make it worse	chemo and bleh bleh bleh, so in
51	for her.	three months' time I might have
		chemo, I might go on Thursday
		and he might say we'll start you
		on chemo on Monday, I don't
		know, you know. Best case
		scenario for me on Thursday is to
		and they say right things have
		moved on a bit, but I'm not
		unduly concerned about it (I –
		mhmm), we're going to give it
		another three month see what
		goes on, that would be fine for
		me, I could cope with that (I –
		yeah), I think. Just
1		
2	Support, partner doesn't	
3	understand why she doesn't	
4	feel able to have sex at the	
5	minute.	
6		
7		
8	Wouldn't like the idea of	
9	wearing a bag either as she	
10	would feel unattractive,	
11	feel restricted in the	
12	clothes that she could wear	
13	feels she would always be	
14	conscious of the bag	have to wait and see (patient is
15	filling up. Doesn't	upset) (I – do you want to take a
16	seem to be aware of	break are you okay?) No I'm
17	alternative such as	fine, I'm just keeping an eye on
18	irrigation or the fact that	the clock sorry. (I – I think we
19	it might only be temporary.	should be okay, what time is it
20		now, quarter past?) I'll need to be
21	Links back to uncertainty,	away from here just after half
22	if she had to have the bag	past. (I – that's fine I've only got

<p>23 on then she would deal  24 with it and get on with it.  25  26  27  28  29  30 Dying – if she was told she  31 had 6 months to live then  32 she would accept it and  33 she could get on with what  34 she has left of her life, even  35 if she wasn't happy with it.  36  37  38  39  40  41  42  43 Hoping that she is given  44 another three months  45 without the chemo.  46  47  48  49  50  51</p> <p>1  2  3  4  5  6  7  8  9  10  11  12  13  14  15  16  17  18  19  20  21  22  23  24  25  26 Changes caused by cancer,</p>	<p>another couple of questions then)  still recording? (I – yeah it's still  recording, yeah.)</p> <p>I - Erm, so, blah, yeah erm you  talked the last time about you  didn't feel like you were living  life, you felt you were just  floating alongside life, you didn't  feel that you knew your body  anymore, erm could you just  explain how that felt, what that  means o you?</p> <p>L – (pause) erm well for me, I'm,  I'm a joiner inner if you like, I get  involved in stuff, erm I'm, I'm  quite a gobby, vocal person and I  get buzzes out of stuff like, what I  find is I just back off most stuff  (now) and I'll just sort of sit in the  background and I'll be like, the  timid little mouse erm which isn't  me, and it's, I can't generate that,  like I was trying to explain to you  before (I – yeah), I can't generate  that feel good factor, I mean I've  had, had, to get the odd fleeting  moment of it erm, but, not to the  same extent that I would have  done in the past, and it's, I still  feel like I'm walking beside kind  of life, I'm not engaging in life,  I'm not (I – right) into the nitty  gritty and, and getting my teeth  behind anything and I'm just like  going through the motions of like  'right oh I'm going dancing  tonight' but</p> <p>there is no oomph about it (I –  yeah), for two pins I would just  stop in but then I know I would  just be sitting here bored stiff, be  sitting thinking about you know  me ailments, and aches and pains  and that and making it worse, at  least when I'm at the dancing I  get up and have a bit of a bop  around, erm and no surprise, don't  think about the pain in the  abdomen (I – yeah) goes away  you know, I think I need bloody  sectioning or, counselling</p>	
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<p>27 she doesn't feel she still  28 gets the same enjoyment  29 out of life  30  31  32  33  34  35  36  37  38 Just feels like she is going  39 along side of life now and  40 that she isn't getting as  41 much enjoyment out of  42 life as she used to  43  44  45  46  47 Going through the motions,  48 doing things because she  49 feels she has to rather than  50 because she wants to.  51</p> <p>1  2 Only reason she doesn't  3 just sit in the house all day is  4 that then their will be nothing  5 to distract her from thinking  6 about cancer  7  8  9 When she is busy she forgets  10 about the aches and pains  11 but she still doesn't enjoy  12 being active.  13  14  15  16  17  18  19  20  21  22  23  24  25  26  27  28  29 Anxiety isn't any better  30 or worse in the last 6</p>	<p>(laughs), need something.</p> <p>I – I mean ehm, talking about the anxiety, just you reminded me there then you said the last time that you would hate to get to the stage where you felt like you needed medication to control the anxiety, is your anxiety any better now, is it any worse, or is it the same?</p> <p>L – (pause) I don't think the anxiety itself is any worse and the worry, anxiety, worry, whatever you want to call it erm I think it's the overall mood (I – mhmm) being down with it has compounded it a bit, I don't actually, because I'm flatter (I – mhmm), I'm not getting as anxious as such, I'm worried, and as I say the tightness and the knots in the stomachs probably related to that (I – yeah) ahm, but it, but it's not stopping is from sleeping and stuff like that, although I wouldn't sleep right through cause I need to get up for the flipping toilet now (I – yeah) during the night erm, but nah I don't. I would say it's probably about the same, if I was, if I was to do a comparison to 6 months ago, it's probably</p> <p>about the same.</p> <p>I –okay, erm just aware of the time then, just one last question, erm you talked about, what I've said is like erm, personalising your cancer like, it wasn't part of you, like you gave a name, so you would call it like Charlie or whatever, so can you just explain the thoughts behind that, why you done that, erm why like you said you said goodbye to your breast before the operation as well, just if you can explain a bit about that and why you done it?</p>	
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<p>31 months but it has changed,  32 feels she is more worried  33 about what is going to  34 happen, and feels that this  35 is exacerbating the aches  36 and pains in her abdomen  37 which makes her worry  38 more.  39  40  41 Isn't affecting her sleep  42 anymore, although she isn't  43 sleeping right through  44 because of the stent anyway  45  46  47  48  49 Feels her anxiety over all is  50 the same as it was 6 months  51 ago.</p> <p>1  2  3  4  5  6  7  8  9  10  11  12  13  14  15  16  17  18  19  20  21 Personalisation of cancer  22 linked to control, was  23 her way of controlling the  24 cancer rather than letting  25 it control her.  26  27 Also ties into her support,  28 felt that it was easier to  29 distance herself from the  30 cancer when she was  31 supported.  32  33  34</p>	<p>L – I think again it was like me  controlling the cancer rather than  the cancer controlling me, erm  cause if I can, control jeez I sound  terrible don't I (I – no that's  okay), erm, it, it with the breast  cancer it was quite clear cut  because the support net...  mechanisms was there erm  everything about the whole  system was good it was positive,  there was support, within the team  over at the hospital the nurses and  everything like that, I could talk  to them, everything that I was  given was in a positive vein, the  vibes and everything was good (I  – mhmm) so I had hope, that big  word, hope. I had hope  throughout, erm and personalising  the cancer was to me right, that  was Charlie, erm it was a way to  grieve for it so that when it went,  it didn't actually have a major  impact on me as a person (I –  okay), whereas the ovarian cancer  I tried to do the same thing but it  just was totally different because,  throughout this whole, nearly two  year now</p> <p>erm, what I've not really felt is  hope )I – mhmm), I've not really  felt positivity, I've not heard the  words 'you'll get through it'  everything has just been matter of  fact and you know blunt. And I  know you can't give people false  hope that, that is wrong to do erm  but the other thing that I have now  and if we can just go and  regressing slightly on the question  of wanting to know basis (I –  mhmm) I think sometimes they  give you too much information (I  – right), now (I –okay) to deal  with cause when I was in the  hospital having the shunt put in,  this woman came in and she was  having her kidney removed  because she had a tumour, I mean  you could hear, even though the  curtains were closed you could  hear what's being said and this  doctor was so blunt about</p>	
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<p>35 36 37 38 39 40 41 42 Naming the cancer let her 43 grieve for it and meant that 44 when the tumour was 45 removed then she could 46 move on from it. 47 48 49 50 51</p> <p>1 Cervical cancer was different, 2 as she felt the support wasn't 3 the same, and she wasn't 4 getting that hope, so she 5 wasn't able to let go as 6 easily – link back to religion 7 praying for hope. 8 9 10 11 12 13 14 15 Information seeking, feels 16 that sometimes the 17 clinicians give too much 18 information and that 19 they should tailor the 20 information to a patient's 21 needs – link to literature 22 surrounding monitors and 23 blunders in health care 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38</p>	<p>everything, she turned to her husband and she said, I am absolutely terrified, she was frightened and she was going down for probably a six hour op (I – mmmm), knowing you know, she might not come out of it, oh you might die on the operating theatre (laughs) thank you, you know! I just think sometimes you know it's about a balance (I – yeah) you know, and experience surgeons and the doctors as well like about gauging who should know what, when (I – yeah) but yeah so I am sorry I digressed slightly (I – no that's fine that's alright yeah).</p> <p>I – Erm so it was a way of like you say just taking control of it?</p> <p>L – It is, it was a control thing and, it was, it was a means of,</p> <p>my way of dealing with it I suppose (I – is it a way of distancing yourself from it, so like as if it wasn't you?) When I was first diagnosed with breast cancer, I definitely did that, I went into work mode, I remember that as clear as day (I – yeah) I just sat there upright, hands crossed, right what do I got to do, and I became the nurse, I wasn't the patient, I was you know whoever erm and took control of it, and you know then got the panic attacks and everything after, I mean I still had issues around that after (I – yeah) and worry that it wasn't going to go right, but when I spoke to the doctors and when I got the support of the nurses, when I was starting to think along these dark thoughts, you know, is it in me lungs, is it in me bones, all of that. Speaking to them and I was getting the feedback, no it's not, you know, obviously they didn't know that until they did the mastectomy (I – yeah) and got rid of the tumour as well, but</p>	
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<p>39 40 41 42 43 44 45 46 47 48 49 50 Again taking control of her 51 cancer</p> <p>1 Coping strategy. 2 3 4 Distance herself from the 5 cancer as if it wasn't 6 happening to her. 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 Still had the anxiety and the 25 thoughts around death the 26 first time, but was getting 27 the positive support 28 that reassured her that 29 she was going to be ok. 30 Didn't get that with the 31 cervical cancer. 32 33 34 35 36 37 38 Feels that the stage cervical 39 cancer was diagnosed with 40 contributed to the 41 negative experience. 42</p>	<p>everything that could have been positive about that experience was, everything was right, me lymph nodes weren't infected, it was caught at the right time. This one had obviously progressed quite rapidly a bit you know before it got to the stage of me picking up on it, so (sighs) and I think in a way you have to, you have to detach yourself from it, maybe by naming it that's what I am doing, it's not a part of me, it's this Mary-Mary, because there was two (I – mhmm), but I haven't revisited my diary (I – okay) for two years. (I – so did you keep a diary), well I did, I kept a diary for Charlie up until</p> <p>the point where I was basically you know finished the chemo and stuff like that and everything was looking positive, so I started a diary with Mary-Mary (I – mhmm), erm I didn't write in it every day, I just you know, would update (I – yeah), but everything about it was, it was just getting out feeling like shite, the doctors were this tablets, can't get nought right it, you know and in the end, I think it was after I did the creative writing thing with Gail (I – mhmm) I just stopped, I thought, I'm tormenting myself even more here, or maybe I'm not acknowledging it, cause by writing it down I was acknowledging how I was feeling, I was getting it out, maybe I should re-visit it and do it that way. Erm, I don't know, but I don't want to go back (I – mhmm) and visit it at the minute. It is in a way like I am trying to ignore it (I – yeah) you know because that's how I want, I want to be able to live, and by that being around, to me it's like, just bringing us down all the time (I – yeah) making me feel unhappy and miserable and, mhmm (I – yeah), yeah so there you go.</p> <p>I – okay, erm, I did have one other</p>	
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<p>43 Feels that naming her  44 cancer was a way of  45 detaching herself from it.  46  47  48 Kept a diary of her  49 experiences but hasn't  50 looked at it since as she  51 thinks it will upset her.</p>	<p>question (L – yeah) but it has  gone out of my mind so I can't  remember what it was I was going  to ask you (laughs) (L – well if  you want to ring us up), yeah I  mean we could do that yea (L –  feel free if it comes back in your  head, haven't drank your water  either) I know that's fine I will get  that in a second. Erm so just to  kind of wrap up then, is there  anything else that you</p>	
<p>1  2  3  4  5  6  7  8  9 Felt her diary second time  10 around was much more  11 negative, stopped writing in  12 it after she went on a  13 creative wiring therapy  14 course as she felt that  15 the diary was tormenting  16 herself.  17  18 However she know feels  19 that by not writing the  20 diary she is not  21 acknowledging it, and  22 not getting her  23 emotions out. This  24 could be contributing to her  25 anxiety.  26  27  28  29  30  31 Feels that she can't enjoy  32 life if she is constantly  33 thinking about her cancer  34 and feels that revisiting her  35 diary will make her feel  36 down and prevent her  37 from doing so.  38  39  40  41  42  43  44  45  46</p>	<p>feel that you want to talk about?</p> <p>L – I was a bit miffed because  Gail had contacted me about the  away day for the mindfulness and  I explained to her what was  happening and erm, and I had  even gone with Eric to find out  where it was at so that I could find  it (I -yeah) and I was in bloody  hospital wasn't I, having the shunt  put in, so I didn't get erm, I mean  I do try and do that and I have, I  must admit I haven't done a scan,  a body scan in a while, I do enjoy  doing them, I do find them helpful  (I – yeah) but I do the you know  in the shower, just being mindful  of the water, and trying to  mindfully walk and things like  that but, I probably don't put it  into practice as much as maybe I  should be doing at the minute,  erm (I – well you've got a lot on  your mind at the minute so) well  it's just been, and I, think the  other thing is that I'm, I'm, I'm  terrible for making links, it's 2013  (I – mhmm), and me dad was  born in 1913, so he would be 100  (I – mhmm) and I'm just thinking  well you know, is this the year I  go, because me dad will be a... I  don't know why I make them  links and I don't even know  where they are coming from, you  know erm (I – yeah), but in me  head I've got somewhere maybe  because it's 2013, that this might  be the year that I am going to die</p>	



47		anyway regardless of what I try
48		and do. No, it's a horrible feeling,
49		(I – I don't imagine that it's nice
50		no) and I mean, I think, in a way I
51		think, I probably would get some
		comfort out of actually being told,
		yes it is, or
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5	Life revolving around	hopefully no it's not you know (I
6	hospital appointments	– yeah) but. Anyway, I'm going
7	away day for her mindfulness	to face the dentist, and I bet I need
8	group fell on a hospital	to pay for this an all (I – yeah, I'm
9	appointment and she	next week for mine so I'm not
10	didn't get to go.	looking forward to it). I couldn't
11		believe it, I thought I could of
12		understood if I had been eating
13		chewy toffees or something stupid
14	Thoughts on dying, making	like that (I – I was eating a
15	connections, because her	cheeseburger, and mines came out
16	father was born in 1913, she	yeah), well I had cooked some
17	feels that that means she	Kentucky chicken, (I -yeah) you
18	will die in 2013.	know southern fried chicken you
19		get in Morrison's (I – yeah) and I
20		had cooked some of that and I just
21		did some chips on Thursday, on
22	Relating back to the fact that	Friday night and I was just sat
23	she thinks this is the	here and chomping away,
24	beginning of the end so is	thoroughly enjoyed it actually and
25	looking for justification for	I went, what the, God. (I – see
26	these thoughts, making	that's what I thought, it was like a
27	sense of it in her head.	bone or something in the, in the
28	Control, feels that if she	burger and then I was like, it took
29	was told she was going to	like five minutes to realise...)
30	die this year then she would	
31	get comfort from that	
32	because then she would	
33	know and she can start to	END OF RECORDING
34	plan around it.	
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## Appendix J – Emergent Theme Table – Lucy – Interview 2

Themes	Page/Line	Key Words
Fear of Recurrence	1.30	Everything was sort of fine, hunky dory then I started getting pains and things again
Professional support	1.38	I saw Dr Smith and they decided to send us for another scan
Fear of recurrence	1.45	It was showing some lesions and shadows and stuff
Recurrence	2.01	In-between the stomach and the pancreas was a little sort of tumour
Professional support	2.07	He decided they could do nothing wait three months and have another scan, or put me on drugs to reduce it
Treatment	2.16	So we did that (drugs)
Uncertainty	2.23	I went back the next week and the results weren't back because you have to give it two weeks
Impact of cancer	2.47	Asked if I would try and take the Tamoxafen as I was struggling to take it, I was feeling sick, off me food
Adjustment	3.07	I now take it at night, and that seems to do the trick to a degree
Future plans	3.09	Went off to America to do the dance competition erm was very wary about going
Impact of cancer	3.12	Me insurance would have been technically invalid
Anxiety	3.18	Blood results indicated there was something wrong could I come to clinic the next day, I'm in America, and he says don't worry come in when you come back
Preoccupation	3.34	So obviously that put a bit of a dampener on the rest of the time but I just tried to put it to the back of me mind
Impact of cancer	3.44	Went and had a scan which showed that the kidney and the ureter had fluid in it
Fear of chemo	4.04	If Tamoxafen doesn't work then looking at chemo again, I hope it's not the same as the last time
Professional support	4.12	Dr Singh wanted me in that day, thought I was starting chemo, was news to me
Professional support	4.37	Dr Smith said he wouldn't be bothered if there was a slight change in me blood markers
Impact of cancer	4.50	I went in three days later and the urologist put the shunt in
Impact of cancer	5.03	Easy operation but it irritates your bladder, well I've got an irritable bladder to start with so..

Emotional impact	5.08	I must admit I am on a right downer at the minute, can't see any light at the end of the tunnel
Fear of death	5.13	Just keep thinking you know, am I going to be here at Christmas
Fear of chemo	5.18	The thought of chemo is just something I really do not wish to have to do again,
Distraction	5.22	It's hard to keep myself motivated, I'm still doing me keep fit have pushed myself to go back
Things getting on top of her	5.27	In amongst that I've got the flu virus, my older brother died, my daughter Charlie she's had abnormal smears
Fear of chemo	6.10	It was horrible, felled me for four, five days, feeling nauseous, can't eat, cramps
Anxiety	6.20	And I do agitate myself and it's just horrendous
Impact of cancer	6.24	You just feel so alone because there is nothing anybody can do for you
Treatment	6.30	I don't think it would be the same as it's only been a year since I finished, think he has something different planned
Biographical Disruption	6.41	And the thought of losing my hair, again, for the third time, just not very nice
Distraction	7.03	When I'm busy and I'm occupied I'm fine
Impact of cancer	7.16	I get windy pains, crampy pains, can get pains from the stent, I've had dodgy bowels since the op
Things getting on top of her	7.32	The flu didn't help that totally felled me, I had no energy for nothing
Emotional Impact	7.42	I used to get a buzz out of stuff, don't get that anymore, side effect of Tamoxifen, mood swings, depression, is it that?
Fear of death	7.47	Am I going to be here, is this the beginning of the end
Guilt	8.04	I don't know if I could cope with that, and I don't want my family coping with it either, I'm going to get upset here
Support	8.09	No you're fine, I'm actually better talking about it
Family Support	8.19	I can't do it with the kids (talk openly), I've got to stay strong because I know how upset they will be
Anxiety	8.26	If he gives us you know oh it's not doing too bad we'll give it another three months, weight off my shoulders
Fear of progression	8.31	If things have progressed, cause I still have all these achy pains, in my mind something is

		going on you know
Impact of cancer	8.38	It could be, I get a lot of wind, and I can't get rid of it, bloody painful
Uncertainty	8.42	The hard bit, I don't know what I am dealing with, you are like in no mans land
Distraction	9.01	Jest get on with stuff, and I try me best, and I do get enjoyment out of things
Impact of cancer	9.07	By 9 o'clock at night I am absolutely shattered, I'm worn out, in bed you know and that isn't me
Anxiety	9.14	I know part of it is the anxiety, that doesn't help, I'm me own worst enemy
Taking control	9.28	I've actually started taking some herbal remedies to try and boost me immune system
Making sense of symptoms	9.34	I've got a horrible taste in me mouth, don't know if its residue from the flu or kidney dysfunction
Impact of cancer	9.45	I had stopped smoking again, but this happened so I am back on the fags again
Preoccupation	10.01	Every other advert seems to be you know people with cancer
Makes sense of symptoms	10.11	Back to the Tamoxafen, I'm tolerating it, whether that's part and parcel of the upset stomach I have no idea
Professional support	10.19	Dr Tyrrell said there were a lot of people worse off than me, but it still doesn't make things nice for me
Anxiety	10.36	Well panicked you know, felt anxiety pit of me stomach straight away, why the urgency?
Fear of death	10.44	You start thinking the worst case scenario, me kidney is packing ing
Uncertainty	10.50	There us too many unanswered questions for me at the minute
Anxiety	11.11	You know he is saying don't worry and it's easier said than done
Distraction	11.14	I mean I did actually put it at the back of my mind, well there isn't anything I can do about it you know
Impact of cancer	11.24	Unconsciously it probably affected me because after that I was even more tired
Impact of cancer	11.34	I was away to bed at 10 o'clock you know which is, I still had a few drinks and stuff but couldn't get enthused
Future plans	11.50	I'm not going back to America, I had already decided that, said that anyway
Religion	12.17	I still do (pray) but not as often, I've thought what's the point it hasn't worked, I need hope of some description

Professional support	12.32	I will see what Dr Smith says but I might not see him it might be Dr Tyrell
Fear of death	13.04	Now I am, it's strange, I think, I hope I don't wake up tomorrow because I don't want to carry on with this
Uncertainty	13.27	I haven't got the knowledge, I don't know what the plan is, seeing different consultants didn't help matters
Fear of chemo	13.42	I just know that I cannot forsee myself for the rest of my days going through purgatory cause that's what chemo is
Future illness	14.02	I would rather be on a bit of morphine, pain free than be curled up feeling sick, and you know enjoy life
Fear of chemo	14.13	I've already told meself that I will give chemo one more go
Hope	14.16	If it is the same as the last time I will be having words, na obviously didn't work the last time, why this time?
Anxiety	14.30	Oh I'm up a height already about Thursday
Coping	15.06	It's about the same there are times where I don't know where I want to be
Distraction	15.16	I've got stuff to do, things to be thinking about like my volunteer job
Loss of Control	15.26	I've just got no control over any of this Grant, and I think that's the problem
Control	15.31	I'm such a control freak that I need to know, but half of us is thinking ignorance is bliss
Information seeking	15.41	I've stopped meself going on there (laptop) and researching stuff because that sets me off
Uncertainty	16.03	Thinking along the lines of, right I can live with one kidney
Hope	16.08	Not many folk who survive pancreatic cancer but if they catch it early enough
Information seeking	16.26	I'll ask the questions I want to ask and sometimes I will get the answers I don't want to hear
Coping	16.34	At the end of the day see how it goes, it's all I can do, day by day really
Family support	16.48	Well as I say there is an unspoken atmosphere not really talking about it
Impact on family	17.02	Think they are dreading Thursday as much as I am
Guilt	17.08	I feel guilty I am putting them through this again, I don't want them having their last memories of me going downhill
Future illness	17.16	Becoming sick all of the time, because that's how I envisage it, just speculating
Family support	17.22	But (partner) is there and I can still get a cuddle off of him if I want one

Fear of death	17.29	I am strong to a point but even I have a point where I just want to crumble
Professional support	17.34	I've got this so called McMillan nurse who suddenly appeared back on the scene again
Professional support	18.09	She knew nothing about me being in hospital
Family support	18.33	She is very blunt, in a way what I need is just somebody to vent to
Family support	19.06	She is there, I can call on her anytime
Death	19.13	The inevitable isn't It, the thoughts in my head will I be here at Christmas, they don't want to talk about it
Control	19.23	I would take control whether they liked it or not I would sit them down
Death	19.32	Well at the end of the day put me affairs in order, most of them are in order anyway
Future plans	19.37	They'll say oh spend your money mam, there is nothing I want to spend it on, what's the point wasting it
Future plans	19.47	The thought of going off on holiday or anything like that, I would be too worried I took ill
Death	20.02	This driving force that I have at the minute, it's hard to shift
Fear of progression	20.07	Especially when I keep getting all these pains, reinforces the belief that something is going on
Future plans	20.31	I've got a holiday booked in August believe it or not
Future illness	20.41	Don't want to spoil anyone else's holiday because I am sitting there with no life or energy
Future plans	21.02	(Partner) is talking about going back down to Torquay in May, and I've got a dinner dance planned in April
Biographical disruption	21.33	My personal perception of myself, body image is not great, see this old hag of a woman staring back at me
Fear of colostomy bag	21.46	Having a colostomy bag would just be another nail in the coffin to me as regards femininity and feeling sexual
Family support	22.02	That's out the window at the minute (sex) and I don't think (partner) understands
Fear of colostomy	22.08	I wouldn't want to wear the bag cause then there's clothes you can't wear
Uncertainty	22.22	Everything is just at the minute, I feel as if I don't know anything
Death	22.30	If they say you've got 6 months left, right fine, not happy about it but I'll know what I'm dealing with
Hope	22.43	Best case scenario for me is they say things have moved on a bit, we'll give it another three

		months
Impact of cancer	23.26	I'm a joiner inner, I get involved with stuff, what I find is I just back off stuff now
Biographical disruption	23.38	I still feel like I am walking alongside of life
Distraction	23.47	I'm going through the motions of like going dancing tonight but there is no oomph about it
Distraction	24.09	When I'm at the dancing I get up and have a bit of a bop around, no surprise I don't think about the pain
Anxiety	24.29	I don't think the anxiety is any worse
Impact of cancer	24.41	It's not stopping us from sleeping although I wouldn't sleep right through cause I need to get up for the toilet
Anxiety	24.49	I would probably say it was about the same as it was 6 months ago
Control	25.21	I think again it was like me controlling the cancer rather than the cancer controlling me
Support	25.27	With the breast cancer it was quite clear cut cause the support mechanisms was there
Moving on	25.42	Personalising the cancer was a way to grieve for it so that when it went it didn't have a major impact
Support	26.01	I've not felt positivity I've not heard the words you'll get through this
Information seeking	26.15	I think sometimes they give you too much information
Control	26.50	It was a control thing and it was a means of, my way of dealing with it I suppose
Coping	27.04	When I was first diagnosed I went into work mode, I became the nurse, I wasn't the patient
Support	27.24	I got the support of the nurses (breast cancer) when I was starting to have these dark thoughts
Impact of cancer	27.38	This one had obviously progressed quite rapidly before it got to the stage of me picking up on it
Detachment	27.43	You have to detach yourself from it, maybe me naming it that's what I am doing
Coping	27.48	I haven't revisited my diary, I kept a diary for Charlie right up til I was finished the chemo
Coping	28.09	Everything about it was getting negative, doctors were this, tablets, can't get nought right
Avoidance	28.18	I'm tormenting meself or maybe I'm not acknowledging it, cause writing it down was acknowledging it
Preoccupation	28.31	I am trying to ignore it, I want to be able to live and by that being around is bringing us down all the time

Future plans	29.05	Away day for the mindfulness and gone to find out where it was, and I was in bloody hospital having the shunt
Death	29.28	I'm terrible for making links, me was born in 1913, so I am thinking is this the year I go
Uncertainty	29.50	I would probably actually get some comfort out of being told yes it is, or no it isn't (the year I will die)



## Appendix K – Superordinate Themes – Lucy – Interview 2

Super ordinate themes – Interview with Lucy		
Themes	Page/Line	Key Words
<b><u>Cancer related Fears</u></b>		
Fear of Recurrence	1.30	Everything was sort of fine, hunky dory then I started getting pains and things again
Fear of recurrence	1.45	It was showing some lesions and shadows and stuff
Recurrence	2.01	In-between the stomach and the pancreas was a little sort of tumour
Fear of chemo	4.04	If Tamoxafen doesn't work then looking at chemo again, I hope it's not the same as the last time
Fear of death	5.13	Just keep thinking you know, am I going to be here at Christmas
Fear of chemo	5.18	The thought of chemo is just something I really do not wish to have to do again,
Fear of chemo	6.10	It was horrible, felled me for four, five days, feeling nauseous, can't eat, cramps
Treatment	6.30	I don't think it would be the same as it's only been a year since I finished, think he has something different planned
Fear of death	7.47	Am I going to be here, is this the beginning of the end
Fear of progression	8.31	If things have progressed, cause I still have all these achy pains, in my mind something is going on you know
Fear of death	10.44	You start thinking the worst case scenario, me kidney is packing in
Fear of death	13.04	Now I am, it's strange, I think, I hope I don't wake up tomorrow because I don't want to carry on with this
Fear of chemo	13.42	I just know that I cannot foresee myself for the rest of my days going through purgatory cause that's what chemo is
Fear of chemo	14.13	I've already told meself that I will give chemo one more go
Fear of death	17.29	I am strong to a point but even I have a point where I just want to crumble
Death	19.13	The inevitable isn't It, the thoughts in my head will I be here at Christmas, they don't want to talk about it
Death	19.32	Well at the end of the day put me affairs in order, most of them are in order anyway
Death	20.02	This driving force that I have at the minute, it's hard to shift

Fear of progression	20.07	Especially when I keep getting all these pains, reinforces the belief that something is going on
Fear of colostomy bag	21.46	Having a colostomy bag would just be another nail in the coffin to me as regards femininity and feeling sexual
Fear of colostomy	22.08	I wouldn't want to wear the bag cause then there's clothes you can't wear
Death	22.30	If they say you've got 6 months left, right fine, not happy about it but I'll know what I'm dealing with
Death	29.28	I'm terrible for making links, me was born in 1913, so I am thinking is this the year I go
<b><u>Consequences of living with and beyond cancer</u></b>		
Impact of cancer	2.47	Asked if I would try and take the Tamoxafen as I was struggling to take it, I was feeling sick, off me food
Adjustment	3.07	I now take it at night, and that seems to do the trick to a degree
Impact of cancer	3.12	Me insurance would have been technically invalid
Anxiety	3.18	Blood results indicated there was something wrong could I come to clinic the next day, I'm in America, and he says don't worry come in when you come back
Preoccupation	3.34	So obviously that put a bit of a dampener on the rest of the time but I just tried to put it to the back of me mind
Impact of cancer	3.44	Went and had a scan which showed that the kidney and the ureter had fluid in it
Things getting on top of her	5.27	In amongst that I've got the flu virus, me older brother died, me daughter Sam she's had abnormal smears
Anxiety	6.20	And I do agitate meself and it's just horrendous
Impact of cancer	6.24	You just feel so alone because there is nothing anybody can do for you
Biographical Disruption	6.41	And the thought of losing me hair, again, for the third time, just not very nice
Impact of cancer	7.16	I get windy pains, crampy pains, can get pains from the stent, I've had dodgy bowels since the op
Things getting on top of her	7.32	The flu didn't help that totally felled me, I had no energy for noting
Emotional Impact	7.42	I used to get a buzz out of stuff, don't get that anymore, side effect of Tamoxafen, mood swings, depression, is it that?

Guilt	8.04	I don't know if I could cope with that, and I don't want my family coping with it either, I'm going to get upset here
Anxiety	8.26	If he gives us you know oh it's not doing to bad we'll give it another three months, weight off me shoulders
Impact of cancer	8.38	It could be, I get a lot of wind, and I can't get rid of it, bloody painful
Impact of cancer	9.07	By 9 o'clock at night I am absolutely shattered, I'm worn out, in bed you know and that isn't me
Anxiety	9.14	I know part of it is the anxiety, that doesn't help, I'm me own worst enemy
Impact of cancer	9.45	I had stopped smoking again, but this happened so I am back on the fags again
Preoccupation	10.01	Every other advert seems to be you know people with cancer
Anxiety	10.36	Well panicked you know, felt anxiety pit of me stomach straight away, why the urgency?
Anxiety	11.11	You know he is saying don't worry and it's easier said than done
Impact of cancer	11.24	Unconsciously it probably affected me because after that I was even more tired
Impact of cancer	11.34	I was away to bed at 10 o'clock you know which is, I still had a few drinks and stuff but couldn't get enthused
Anxiety	14.30	Oh I'm up a height already about Thursday
Loss of Control	15.26	I've just got no control over any of this Grant, and I think that's the problem
Impact on family	17.02	Think they are dreading Thursday as much as I am
Guilt	17.08	I feel guilty I am putting them through this again, I don't want them having their last memories of me going downhill
Biographical disruption	21.33	Me personal perception of meself, body image is not great, see this old hag of a woman staring back at me
Impact of cancer	23.26	I'm a joiner inner, I get involved with stuff, what I find is I just back off stuff now
Biographical disruption	23.38	I still feel like I am walking alongside of life
Anxiety	24.29	I don't think the anxiety is any worse
Impact of cancer	24.41	It's not stopping us from sleeping although I wouldn't sleep right through cause I need to get up for the toilet
Anxiety	24.49	I would probably say it was about the same as it was 6 months ago
Impact of cancer	27.38	This one had obviously progressed quite rapidly before it got to the stage of me picking up on it

Anxiety	24.49	I would probably say it was about the same as it was 6 months ago
Preoccupation	28.31	I am trying to ignore it, I want to be able to live and by that being around is bringing us down all the time
<b><u>Coping with life after treatment</u></b>		
Professional support	1.38	I saw Dr Smith and they decided to send us for another scan
Professional support	2.07	He decided they could do nothing wait three months and have another scan, or put me on drugs to reduce it
Treatment	2.16	So we did that (drugs)
Uncertainty	2.23	I went back the next week and the results weren't back because you have to give it two weeks
Professional support	4.12	Dr Singh wanted me in that day, thought I was starting chemo, was news to me
Professional support	4.37	Dr Smith said he wouldn't be bothered if there was a slight change in me blood markers
Distraction	5.22	It's hard to keep myself motivated, I'm still doing me keep fit have pushed myself to go back
Distraction	7.03	When I'm busy and I'm occupied I'm fine
Support	8.09	No you're fine, I'm actually better talking about it
Family Support	8.19	I can't do it with the kids (talk openly), I've got to stay strong because I know how upset they will be
Uncertainty	8.42	The hard bit, I don't know what I am dealing with, you are like in no man's land
Distraction	9.01	Jest get on with stuff, and I try me best, and I do get enjoyment out of things
Taking control	9.28	I've actually started taking some herbal remedies to try and boost me immune system
Making sense of symptoms	9.34	I've got a horrible taste in me mouth, don't know if its residue from the flu or kidney dysfunction
Makes sense of symptoms	10.11	Back to the Tamoxafen, I'm tolerating it, whether that's part and parcel of the upset stomach I have no idea
Professional support	10.19	Dr Tyrrell said there were a lot of people worse off than me, but it still doesn't make things nice for me
Uncertainty	10.50	There us too many unanswered questions for me at the minute
Distraction	11.14	I mean I did actually put it at the back of my mind, well there isn't anything I can do about it

		you know
Religion	12.17	I still do (pray) but not as often, I've thought what's the point it hasn't worked, I need hope of some description
Professional support	12.32	I will see what Dr Smith says but I might not see him it might be Dr Tyrrell
Uncertainty	13.27	I haven't got the knowledge, I don't know what the plan is, seeing different consultants didn't help matters
Hope	14.16	If it is the same as the last time I will be having words, na obviously didn't work the last time, why this time?
Coping	15.06	It's about the same there are times where I don't know where I want to be
Distraction	15.16	I've got stuff to do, things to be thinking about like my volunteer job
Control	15.31	I'm such a control freak that I need to know, but half of us is thinking ignorance is bliss
Information seeking	15.41	I've stopped meself going on there (laptop) and researching stuff because that sets me off
Uncertainty	16.03	Thinking along the lines of, right I can live with one kidney
Hope	16.08	Not many folk who survive pancreatic cancer but if they catch it early enough
Information seeking	16.26	I'll ask the questions I want to ask and sometimes I will get the answers I don't want to hear
Coping	16.34	At the end of the day see how it goes, it's all I can do, day by day really
Family support	16.48	Well as I say there is an unspoken atmosphere not really talking about it
Family support	17.22	But (partner) is there and I can still get a cuddle off of him if I want one
Professional support	17.34	I've got this so called McMillan nurse who suddenly appeared back on the scene again
Professional support	18.09	She knew nothing about me being in hospital
Family support	18.33	She is very blunt, in a way what I need is just somebody to vent to
Family support	19.06	She is there, I can call on her anytime
Control	19.23	I would take control whether they liked it or not I would sit them down
Family support	22.02	That's out the window at the minute (sex) and I don't think (partner) understands
Hope	22.43	Best case scenario for me is they say things have moved on a bit, we'll give it another three months
Distraction	23.47	I'm going through the motions of like going dancing tonight but there is no oomph about it
Distraction	24.09	When I'm at the dancing I get up and have a bit of a bop around, no surprise I don't think about

		the pain
Control	25.21	I think again it was like me controlling the cancer rather than the cancer controlling me
Support	25.27	With the breast cancer it was quite clear cut cause the support mechanisms was there
Moving on	25.42	Personalising the cancer was a way to grieve for it so that when it went it didn't have a major impact
Support	26.01	I've not felt positivity I've not heard the words you'll get through this
Control	26.50	It was a control thing and it was a means of, my way of dealing with it I suppose
Coping	27.04	When I was first diagnosed I went into work mode, I became the nurse, I wasn't the patient
Support	27.24	I got the support of the nurses (breast cancer) when I was starting to have these dark thoughts
Detachment	27.43	You have to detach yourself from it, maybe me naming it that's what I am doing
Coping	27.48	I haven't revisited my diary, I kept a diary for Charlie right up til I was finished the chemo
Coping	28.09	Everything about it was getting negative, doctors were this, tablets, can't get nought right
Avoidance	28.18	I'm tormenting meself or maybe I'm not acknowledging it, cause writing it down was acknowledging it
<b><u>Future Disorientation</u></b>		
Future plans	3.09	Went off to America to do the dance competition erm was very wary about going
Future plans	11.50	I'm not going back to America, I had already decided that, said that anyway
Future illness	14.02	I would rather be on a bit of morphine, pain free than be curled up feeling sick, and you know enjoy life
Future illness	17.16	Becoming sick all of the time, because that's how I envisage it, just speculating
Future plans	19.37	They'll say oh spend your money mam, there is nothing I want to spend it on, what's the point wasting it
Future plans	19.47	The thought of going off on holiday or anything like that, I would be too worried I took ill
Future plans	20.31	I've got a holiday booked in August believe it or not
Future illness	20.41	Don't want to spoil anyone else's holiday because I am sitting there with no life or energy
Future plans	21.02	(Partner) is talking about going back down to Torquay in May, and I've got a dinner dance planned in April
Uncertainty	22.22	Everything is just at the minute, I feel as if I don't know anything

Future plans	29.05	Away day for the mindfulness and gone to find out where it was, and I was in bloody hospital having the shunt
Uncertainty	29.50	I would probably actually get some comfort out of being told yes it is, or no it isn't (the year I will die)

### Appendix L – Master table of super-ordinate themes and sub-themes

<u>Cancer Related Fears</u>		<u>Consequences of living with and beyond cancer</u>	
Fear of recurrence		Infertility as a result of cancer	Impact on Family Life
Fear associated with an uncertain future		Loss of Control	Occupational Impact
Fear of the impact of treatment		Recurrent thoughts related to cancer	Physical Consequences of cancer
		Anxiety	
<u>Coping with life after treatment</u>		<u>Future Disorientation</u>	
Making Sense of symptoms	Hope	Future Plans	
Lifestyle Adjustments	Formal Support	Feelings of not recovering from cancer	
Psychological/Emotional Adjustment	Social Support	Life on Hold	
Religion/Spirituality			