

# **“Ahead on points”: Understanding the long-term impact of colorectal cancer with liver metastases on quality of life and survivorship experiences**

**Katie Whale**

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Faculty of Health and Applied Sciences, University of the West of England, Bristol

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# Introduction to the thesis and systematic review

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This thesis is written for the qualification of Professional Doctorate in Health Psychology. The focus of this thesis is exploring the long-term impact of colorectal cancer with liver metastases on quality of life and survivorship experiences in individuals at least 5 years post-surgery. In addition, the relevance of the current EORTC quality of life questionnaires used in this population is considered.

In line with the competency requirements a systematic review was conducted in year 1. The title of this systematic review is 'The impact of rheumatoid arthritis on body image: a systematic review'. The review was conducted to investigate whether rheumatoid arthritis had a negative effect on body image. Findings relating to the impact of rheumatoid arthritis on body image were inconsistent, however a relationship between age of onset and body image was found, with earlier onset being associated with greater body dissatisfaction.

Originally I had planned to conduct a research project in this area, however due to starting a new Research Associate post at the University of Bristol School for Social and Community Medicine, this was not possible.

As focus of this review is not relevant to the thesis it is not included in the main body and can be seen in appendix 7. The skills gained in conducting this review relating to identifying relevant literature, critically appraising the methodology of existing studies, and synthesising evidence were implemented in the undertaking of this thesis. An additional in-depth literature review was conducted to inform the research programme (see pages 3-12).

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# Abstract

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The aim of this study was to investigate the impact of colorectal cancer (CRC) with liver metastases on long-term quality of life (QOL) and survivorship experiences, and to explore the relevance of the EORTC QOL questionnaires to this population, using a qualitative approach. Overall 15 participants were interviewed, 5 women and 10 men. Interviews were analysed using inductive thematic analysis. Three main themes were identified: Cancer and me: establishing a relationship with cancer; Living with cancer; and Aligning the long-term impacts: the person I've become.

The results illustrate that CRC survivors with liver metastases define QOL in different ways and have a broad and diverse range of experiences. As long-term cancer survivors, the focus on short-term physical symptoms is no longer relevant. Instead, the relationship with cancer, development of coping strategies, and coming to terms with a post-cancer self are of far more importance.

As QOL is a subjective experience, there is no 'one size fits all' approach to definition and measurement. Health care professionals and policy makers need to understand the variety in meaning and be clear about the purpose of QOL measures. In attempts to promote long-term positive adjustment, cancer survivors may benefit from a wider range of support and expertise. Health Psychologists in particular could offer valuable insight and support in relation to adaptive coping strategies, mental framing, adjustment to physical changes, and the development and adjustment to the 'post-cancer self'. Future work would benefit from holistic definition of QOL and from using a broad range of assessment techniques.

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# Introduction

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The current study is focused on investigating the long-term impact of colorectal cancer with liver metastases on quality of life and survivorship experiences.

## Colorectal cancer

Colorectal cancer (CRC) is a major health problem with approximately 41,000 cases in the UK annually. It is the fourth most common cancer in the UK with 95% of cases occurring in people aged 50 and over (Cancer Research UK, 2014). In colorectal cancer, cells in the colon or rectum mutate and grow to form a primary tumour. Symptoms of colorectal cancer can include bleeding from the rectum, changes in bowel habits such as diarrhoea or looser stools, pain in the abdomen or rectum, and weight loss (Cancer Research UK, 2014).

CRC is the second most common cause of cancer death in the UK after lung cancer. Survival rates and long-term outcomes are dependent on the stage of the disease at diagnosis. For patients diagnosed at an early stage the five-year survival rate is 93.2%, however this falls to 47.7% for regional disease involving the lymph nodes and 6.6% for those with metastatic cancer (National Cancer Intelligence Network, 2009).

The incidence of CRC increases with age. In the UK between 2009 and 2011, 43% of CRC cases were diagnosed in patients over 75 years old, and 95% in those over 50 years old. CRC is also more common in men with 56% of new cases being diagnosed in males in 2011 compared to 44% in females. Lifestyle factors are linked to 54% of cases. Increased red and processed meat consumption, overweight and obesity, alcohol and smoking are all linked to greater risk of CRC (Cancer Research UK, 2015).

CRC can be diagnosed in a number of ways. Initial investigations will normally involve an examination of the abdomen and rectum to check for any lumps. Further investigations are then carried out by flexible sigmoidoscopy involving a thin tube and camera being inserted into the rectum. The majority of cases can be diagnosed using this method, however cancer occurring higher up in the colon or bowel require a colonoscopy (NHS, 2014).

The primary treatment for CRC is surgery to remove the tumour. Depending on the stage and location of the tumour, this may also be combined with chemotherapy, radiotherapy or biological treatments.

## Colorectal cancer with liver metastases

Approximately 30-40% of patients with CRC develop liver metastases, which are detected either when the primary colorectal tumour is diagnosed or develop during follow-up after initial treatment (Cancer Research UK, 2014; National Cancer Intelligence Network, 2009). Survival rates for CRC with liver metastases are low, typically 6.6% at 5 years.

Treatment options vary depending on the extent of the metastatic disease, however liver metastases are most successfully treated by surgery combined with chemotherapy, radiofrequency ablation, or cryotherapy. Approximately 30-40% of patients are suitable for surgical treatment aimed at cure (Scheele, Stang, Altendorf-Hofmann & Paul, 1995), however to be eligible for this treatment both the primary CRC and the liver metastases must be fully resectable. Patients undergoing curative surgical treatment have a survival rate of 15-40%, and up to 70% in patients with favourable disease markers (Nordlinger et al., 1996; Blazer et al., 2008; Rees, Tekkis, Welsh, O'Rourke & John, 2008). In contrast, patients who are not suitable for resection may receive palliative chemotherapy or local ablative treatments and have much poorer survival (Patel et al., 2012). The aim of these treatments is to control symptoms, maintain or improve quality of life and prolong survival.

## Quality of life: definition, assessment and measurement

Evaluation of hepatic resection for CRC metastases has traditionally included measurement of survival and surgical morbidity; however there is now significant interest in assessing quality of life (QOL). In conditions such as CRC, QOL can offer insight into both the benefits and burdens of treatment. Together with classical assessments of survival, disease recurrence and frequency of complications, QOL assessment can provide a comprehensive measurement of the effects of surgery by capturing both patients' experiences and patient reported outcomes (PROS). This assessment 'package' is purported to offer important information for patients, carers, surgeons and health policy makers and to offer data relevant to informing treatment decision making, to support informed consent, provide key information to manage patient and carer expectations prior to and after surgery (Bottomley, et al., 2005; de Haes et al., 2000; Blazeby et al., 2006), and may also help plan service provision.

Despite the increasing interest in QOL and its use in evaluating the quality and outcome of health care, there is still a lack of consensus about the construct (Moons, Budts & De Geest, 2006). A number of articles have discussed the conceptualisation of QOL and the differences in conceptual approaches across disciplines (e.g. Bakas et al., 2012; Theofilou, 2013). The heterogeneity in the definition and conceptualisation of QOL creates significant challenges for assessment and



measurement, for without first understanding what QOL means to an individual or a particular population, we cannot seek to measure it in a way that is equally as meaningful.

### **Objective versus subjective dimensions**

An on-going discussion relating to QOL measurement is the relationship between objective and subjective dimensions. Traditionally, objective dimensions refer to physical or observable phenomena that can be measured by an impartial observer, for example, the ability to walk or eat, whilst subjective dimensions refer to an individual's perception, such as satisfaction with life and overall happiness. Questionnaire-based measures of QOL often include both objective dimension such as presence or absence of symptoms, and subjective dimensions such as emotional wellbeing or social satisfaction. Due to inclusion of both types of dimension, defining a QOL measure as objective or subjective is complex. However, an argument can be made that it is the method of measurement, rather than the content, that defines a QOL measure as objective or subjective.

Existing questionnaire-based measures of QOL are primarily developed through standardised models using preselected discrete quantitative domains (Carr & Higginson, 2001). An individual's QOL is determined by how well they align to the predefined idea of what QOL is and which areas of QOL the 'measurer' feels are most important. By providing set criteria for what QOL is dependent upon, individuals can then be grouped into those whose scores indicate that they have 'good' QOL and those who do not. Whilst these measures may include dimensions that are traditionally seen as subjective, such as social function or emotional wellbeing, the restriction to a preselected set of dimensions which offer only one definition and interpretation of QOL arguably makes them objective. The chosen dimensions may not correspond to individuals' definition of what QOL means to them, or their interpretation of a 'good quality of life'. Instead, these measures only provide an insight in how well they align with what the measurer believes QOL to be. Truly subjective measures could therefore not offer any predefined dimension of what QOL is or be broken down into quantitative scores, as each individual may have a different perception of what QOL means to them.

An added complication to the distinction between objective and subjective measures in QOL is the use of patient-reported outcome measures (PROMs). These are measures which have been designed in collaboration with the patient with content based on what the chosen patient group feels to be important. As these measures are designed by patients themselves, they offer additional insight into what patients groups feel are important to measure in relation to QOL, rather than what clinicians or other health professionals may assume is important. However, despite the inclusion of patients in the design of the measures, the method of measurement using

set, preselected dimensions to which individuals are measured against, still aligns with an objective methodology.

Using this viewpoint, quantitative questionnaire-based measures of QOL can never be subjective as they offer a narrow definition of QOL for individuals to be assessed against. Whilst PROMs may go some way in helping to address this, there is no guarantee that other patients will feel the same way. To be truly subjective, a QOL measure must offer individuals the opportunity to define what QOL means to them, and then to assess whether they perceive themselves to have a good QOL or not based on this definition.

Objective models often use health status as a proxy for QOL, focusing on loss and deviation from a healthy norm. This approach views QOL as a primarily functional concept, defined as the absence of limitation in functional abilities, mental health, and life expectancy (Clarke & Bowling, 1989), as measured against a healthy norm. This is most commonly referred to as 'health related quality of life' (HRQL). Using this approach, individuals with a significant health condition, such as cancer, can never achieve a high QOL as medically they do not have full physical health.

HRQL has become an increasingly prevalent measure in health research, particularly in studies investigating QOL in cancer patients. It could be argued that the rise in the use of HRQL is linked to the increasing need to provide concrete evidence of treatment effectiveness in order to secure funding and financial backing. Due to the ever-increasing budget cuts within the health system, researchers and medical practitioners are under constant pressure to demonstrate value for money. Policy making and resource allocation decisions within health rely heavily on quantitative evidence of cost-effectiveness and value. This is especially true when comparing different treatment options or interventions which are to be made available to the public through the National Health Service (NHS).

One of the core judgements that is often made when deciding on a treatment course is the balance between expected value to the patient in terms of survival, versus the quality of this survival time. This is referred to as Quality Adjusted Life Years (Williams, 1988). In each treatment or intervention programme, the benefit to the patient can be divided by its economic cost in order to inform resource allocation (Spiegelhalter et al., 1992; King, Tsevat, Lave & Roberts, 2005). Due to the limited healthcare budget, this information is then used to decide which treatments may be offered to a particular group of patients, such as those with CRC, or even which groups of patients or health programmes are most deserving of funding.

With this focus on the importance of evidence-based assessment in order to secure funding and support within the health care system, objective assessments of HRQL have taken centre stage. However, despite the need to have accountable decision-making processes within health policy, by using HRQL in the assessment of treatment and intervention effects, the multidimensional nature of QOL is arguably reduced to a measure of health economics (Fitzpatrick et al., 1992). Subjective dimensions of QOL and the importance of wider issues and individual experience become marginalised. In turning patients into units of measurement and cost, the patient voice becomes lost. In addition, these measures only provide information on the short-term costs of initial treatment and care. Very little information is available on longer-term patient needs within the health service, such as on-going psychological support, carer burden and costs, and access to secondary care services.

The current conceptualisation and measurement of HRQL finds its roots in the WHO definition of health. The current WHO definition of health, as put forward in 1948, describes health as “a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity” (WHO, 2003, p.100). However, this definition, and its application to QOL, has come under considerable criticism in recent years (Huber et al., 2011). Within the current ageing population and increasing medicalisation of society, the focus on ‘complete health’ situates much of the population in the ‘unhealthy’ bracket. Due to advances in healthcare and better management of disease, the number of people across the world living with chronic health conditions has increased (Huber et al., 2011). Due to these changes in population health, it can be argued that the current WHO definition of health is out-dated and in need of reformulation.

The assumption that reduced or impaired health always means reduced QOL is significantly flawed. It has been shown that individuals with serious health and functional problems do not necessarily demonstrate poor QOL (Carr & Higginson, 2001). Indeed, studies of cancer patients have shown that experiencing and surviving cancer can create an increased appreciation of life resulting in higher QOL compared to that of a healthy population (e.g. Danoff, Kramer, Irwin & Gottlieb, 1983; Taylor, Lichtman & Wood, 1984; Fromm, Andrykowski & Hunt, 1996).

For QOL definitions and measures derived from purely objective dimensions, the question arises as to whether this can fully capture the uniqueness of individual experience. While it can be argued that there may be a set of core dimensions which all play a part in an individual’s QOL, the relative importance of each of the dimensions varies between individuals (Felce, 1997). As individuals differ in what they feel is important in their lives and what it means to live a happy and fulfilled life, their interpretation of QOL will also be different. Within the literature there is a

growing consensus that QOL is therefore a subjective experience (Cella, 1998; Haas, 1999, Moons et al., 2006).

As previously stated, subjective measures of QOL focus on an individual's satisfaction with their life and do not rely on any one definition of what QOL means. Rather than viewing QOL as determined by an individual's objective life condition, the subjective approach focuses on exploring QOL as an individual's subjective appraisal of their life condition (Moons et al., 2006). This viewpoint is supported by the notion of the 'disability paradox' (Levine, 1987; Albrecht & Devlieger, 1999). In a move away from the biomedical model of illness, the disability paradox illustrates that physically disabled individuals can still report a good or excellent QOL, even though their objective condition may appear negative. Using a more holistic approach, QOL is shown to depend on striking a balance between body, mind, and spirit, and on establishing meaningful connections with other individuals and the external environment. The extent to which physical disability hinders QOL is determined by the extent to which individuals incorporate this into their sense of self. For some, their physical status and wellbeing is a core aspect of their personal identity and therefore a key determinant in their satisfaction with life. For others it is seen as one aspect of their life that has little bearing on their personal identity. This approach is further supported by literature on visible differences which shows that it is not the severity of the condition, but how an individual perceives and adjusts to it that determines the overall impact (Moss, 2005; Ong et al., 2007; Feragen, Kvaem, Rumsey & Borge, 2010; Brown, Moss, McGrouther & Bayat, 2010).

### **Changes in QOL over time**

In addition to the on-going debate surrounding the conceptualisation of QOL, a further aspect to consider is that it is not a static state of being, but rather that it changes over time. Not only does an individual's level of satisfaction with their QOL have a temporal aspect, but what it means to that individual and which aspects are most important may also change (Sprangers & Schwartz, 1999). The 'response shift model' (Sprangers & Schwartz, 1999) describes how internal standards, values and conceptualisation of QOL can change over the course of disease trajectory. In other words, both what is important and how important something is change over time. For example, a 'healthy' person may consider losing the ability to control his or her bowels as being a complete obstacle to having a high quality of life, however someone who has been diagnosed with CRC may come to adapt to this change and still report a positive QOL. Indeed, evidence of this response shift has been demonstrated in CRC patients through exploration of a multilevel model of QOL (Lowy & Bernhard, 2004).

The evidence that QOL changes over the time presents a key criticism of objective questionnaire measures. Although these measures may account for changes in the levels of various aspects of QOL, they do not account for changes in the weight of importance or salience of these different aspects.

### **Positive versus negative changes**

A further criticism of the current definitions and measurement of QOL and HRQL in health research is that they are measured in reduction and limitation rather than in positive gains. The majority of health research investigating QOL is concerned with the negative impacts of a health condition or treatment on a previous QOL baseline. Although this can offer valuable insights into patient experience, or how certain conditions can impact on an individual's life experience, it can be argued that this approach is only telling half the story (Moons et al., 2006). Many studies of cancer patients have shown positive changes as a result of their cancer, such as a renewed appreciation for life, increased compassion and empathy, and increased personal resilience (e.g. Danoff et al., 1983; Fromm et al., 1996; Taylor et al., 1984; Tempelaar et al., 1989, Horgan, Holcombe & Salmon, 2011).

The positive impact of cancer is also illustrated in the literature on post-traumatic growth. Post-traumatic growth refers to the experience of positive change as a result of a highly challenging life event or trauma (Calhoun & Tedeschi, 1999, 2001). This can include a renewed appreciation for life, development of more meaningful intrapersonal relationships, and new found or extended spiritual or religious life. Post-traumatic growth is not restricted to cancer experiences, however given the severity and often life-threatening nature of the disease, much research has been conducted with this population. Cross-sectional work conducted with breast cancer patients has shown that individuals who had experienced high perceived life-threat demonstrated increased post-traumatic growth when compared to a healthy population (Cordova et al., 2001).

### **Quality of life after liver surgery for hepatic metastases from colorectal cancer**

Despite the on-going debate surrounding the conceptualisation and measurement of QOL, it is still a key outcome in health research, particularly in relation to cancer patients. Work exploring QOL after liver surgery for CRC liver metastases is still very limited, with the majority of studies focusing on short-term HRQL, and very little work being carried out exploring the long-term impact or on patient perceptions of QOL and individual differences.

A small number of quantitative questionnaire based studies have been published on HRQL after liver resection for CRC liver metastases, however they often include patients undergoing liver surgery for other conditions, and have very poor questionnaire compliance rates (Langenhoff, Krabbe, Peerenboom, Wobbles & Ruers, 2006; Dasgupta et al., 2008; Martin, Eid, Scoggins & McMasters, 2007; Banz, Inderbitzin, Fankhauser, Studer & Candinas, 2009). A systematic review of patient reported outcomes before and after liver surgery for hepatic metastases for CRC conducted in 2012 by Rees identified 6 studies all including a measure of QOL. This included 5 prospective cohort studies (Langenhoff et al., 2006; Martin et al., 2007; Dasgupta et al., 2008; Weiring et al., 2011; Rees et al., 2012) and 1 longitudinal case series (Banz et al., 2009). Of these only 3 exclusively reported on colorectal cancer liver metastases (Langenhoff et al., 2006; Weiring et al., 2011; Rees et al., 2012). Langenhoff et al. and Rees et al. both investigated HRQL using the European Organisation for Research and Treatment of Cancer Quality of life Questionnaire–C30, (EORTC QLQ-C30) with Rees et al. using the additional Quality of Life Questionnaire-Liver metastases C21 (EORTC QLQ-LMC21) and Langenhoff et al. the EuroQoI-5D (EQ-5D). Both studies found global and functional HRQL to decrease after surgery, with scores returning to baseline levels at 6 months post-surgery, however Rees et al. found that some patients still reported reduced sexual function, tingling in fingers, anxiety, and problems with activity and vigour at 12 months post-surgery. Weiring et al. only used the EQ-5D and reported mild decreased in HRQL 6 weeks after surgery, with scores returning to baseline levels at 3 months.

One study has followed up patients over the 1-year mark. Rees et al. (2014) conducted a further analysis at 5 years post-surgery using the same surviving patient group and HRQL measures. At 5 years post-surgery functional scores were higher than original baseline levels demonstrating improvements in emotional, social, and role functioning as compared to before surgery. However, persistent severe symptoms were reported in sexual function, peripheral neuropathy, constipation, and diarrhoea in some patients.

The results from these studies clearly demonstrate that liver surgery in CRC patients with liver metastases has a significant impact on short-term HRQL. Although global and functional scales are shown to return to baseline levels a year after surgery, many symptoms such as sexual function, anxiety, and peripheral neuropathy still persist at 1 year post-surgery with sexual function, peripheral neuropathy, constipation, and diarrhoea found to persist at 5 years post-surgery. However, as these studies primarily focus on short-term HRQL they can tell us very little about patients' wider perceptions of QOL, or long-term QOL. As previously discussed, the narrow definition of QOL as relating to physical health status does not capture detailed information on patient experience. In order to do this a flexible qualitative approach is necessary.

A single US study qualitatively assessed patient experiences after liver surgery for colorectal liver metastases to identify common themes. This study aimed to identify factors of importance in treatment decision-making using a phenomenological approach. It identified the health care provider, support from others, the patients' own attitude, cure uncertainty, coping strategies, hospital care concerns and internet information as important themes in the treatment decision making process (McCahill & Hamel-Bissell, 2009). However, it did not explore long-term quality of life or post-surgery survivorship experiences.

## **Cancer survivorship**

Cancer survivorship faces many of the same challenges as QOL in terms of definition and usage. Although it is a widely used term, there is little consistency in meaning and application across the literature (Khan, Rose & Evans, 2011). In some cases survivorship is used interchangeably with survival, in others it is used as an umbrella term for on-going HRQL issues after treatment and post-treatment health care needs (Salz et al., 2014), and in others it is more closely aligned with personal identity (Deimling, Bowman & Wagner, 2007).

The term 'survivorship' was first coined by an American Physician in a paper published in 1985 on his own experiences with cancer, and focused on defining the course of cancer (Mullan, 1985). This term was used because it encompassed both those who could be considered 'cured', and those still undergoing treatment. Mullan argued that rather than seeing these as two disparate groups, there were many commonalities in experiences and on-going issues. Although usage of the term in the context of more recent advocacy work has purely focused on the positive aspects of 'beating' cancer (Deimling et al., 2007), there has been a move back towards the original focus on both patients who are undergoing treatment and those in remission, and on both positive experiences and the enduring problems which cancer patients experience (Khan et al., 2012).

As well as recognition that survivorship can encompass both positive and negative aspects, literature has been published look at the link between survivorship and identity. Previous research has suggested that experiencing cancer may elicit changes in identity, primarily based on a new illness-related view of the self (Little, Paul, Jordens & Sayers, 2002; Zebrack, 2000). Identity theory explores the concept that individuals attach varying degrees of salience to certain aspects of their identity, and the stability of this pattern of salience over time (Thoits, 1991). Significant life events, such as experiencing a life-threatening illness, can result in changes to the relative importance of different aspects of identity. This in turn can lead to changes in how individuals view themselves and also to their self-concept (Deimling et al., 2007). One of the key mechanisms for this change is through impaired role performance (Frank, 1991; Mathieson & Stam, 1995). Cancer treatment can have a considerable impact on individuals' ability to continue with roles

that may be central to their identity, for example career performance, partner or spouse relationships, or childcare. When their ability to perform these roles is hindered, a core aspect of their self-concept is taken away. In order to adjust to these changes, many adopt a new illness-related identity.

Although survivorship has become an increasingly common term within the cancer literature, studies have shown that some individuals resist identifying themselves as 'cancer survivors'. In a study of women with breast cancer, it was found that many women felt the term to be overly heroic and failing to account for the possibility of recurrence (Kaiser, 2008). Women felt alienated by this term and reported that they didn't believe their cancer was severe enough to merit this title. Findings such as these suggest that current understanding of survivorship, and whether this term is relevant to cancer patients, is still lacking and merits further investigation.

Literature exploring survivorship in CRC patients with liver metastases is lacking, however studies have been published focused solely on non-metastatic CRC. The majority of this literature uses the term survivorship to describe the participant sample rather than the experiences of patients in relation to their identity. In these studies CRC cancer survivorship is operationalised as CRC patients who are in remission or can be considered 'cured', with a primary aim of understanding the on-going care needs of this population. Rather than exploring what survivorship means to these individuals, the main focus is on on-going QOL domains such as symptoms, mental wellbeing, social wellbeing, psychosocial issues, and wider issues such as body image (Denlinger & Barsevick, 2009; Faul, Shibata, Townsend & Jacobsen, 2010; Denlinger & Engstrom, 2011; Averyt & Nishimoto, 2014).

Some work has been conducted using a wider definition of survivorship. A qualitative study including CRC patients 6 months to 5 years post-treatment adopted an interpretive phenomenological approach to investigate the experience, meaning, concerns and strategies used by these patients during a defined survivorship period of 5 years post-treatment (Appleton, Goodlad, Irvine, Poole & Wall, 2013). The study showed that CRC survivors used a broad range of approaches to adjust to life after cancer treatment, including goal setting, practical changes, and mental mind-set. The study also explored how participants felt about their strategies for coping with treatment and their feelings about surviving cancer. Participants discussed using humour and having a positive outlook, and the importance of maintaining a normal routine. In relation to feelings about survival, some participants were reported to describe feeling 'indestructible' whilst others talked about their challenges with depression and coming to terms with their new identity.



The recognition of the challenges faced by cancer survivors has increased in recent years, particularly in cancer care services. The National Cancer Survivorship Initiative (closed in March 2013), and the successive Living with and Beyond Cancer Programme, offer support and advice not only to cancer survivors, but also health care professionals and commissioners. The primary aim of these initiatives is to inform the future direction of survivorship work in England through outlining the current knowledge of survivorship, the needs of survivors, and interventions which have been shown to improve survivors' outcomes.

## **Why is the current study needed?**

There is an increasing interest in QOL and its use in evaluating the quality and outcome of health care. In conditions such as CRC, QOL can offer insights into both the benefits and burdens of treatment, and the impact of this on patients' lives. Understanding how illness experiences affect patients can provide important information for carers, health professionals, and health policy makers, and can provide key information in managing patient and carer expectations prior to and after surgery (Bottomley, et al., 2005; de Haes et al., 2000; Blazeby et al., 2006). Understanding how patients' needs and experiences change over time is also key in providing appropriate care and support, not only from health professionals but also from patients' families and social groups. In addition, as CRC with liver metastases has low survival rates and limited life expectancy for some individuals, there is a greater urgency for understanding patient experience compared to other populations.

It is clear that within the current literature there is a paucity of research on the long-term impact of CRC with liver metastases on QOL. Studies that have been published are primarily quantitative and focus on questionnaire based HRQL findings using a narrow functional and health status definition of QOL, and rarely follow up patients beyond one year post-surgery. Although this can give a valuable insight into how treatment may affect patients physically in the short-term, it does not provide any insight into their wider experiences over the long-term.

As previously discussed, there is on-going debate surrounding what QOL means and how it can be measured. Although little consensus has been achieved, it can be broadly stated that it is a multidimensional construction, composed of objective and subjective dimensions, the importance of which varies between individuals, and over time within individuals. With this definition in mind, it is clear that in order to fully capture the details and nuances of QOL in CRC patients who have undergone liver surgery, an open and flexible approach is key. Current questionnaire measures would limit the scope of investigation and impose pre-defined ideas of what QOL means to these patients. Therefore a semi-structured qualitative approach is needed to gain insight into the experiences of this patient group, and allow the flexibility to explore how their QOL has been

affected, and how this may have changed over time. Not only will this provide more detailed understanding of experiences within the patient group, but will also contribute to broader debates about the conceptualisation and measurement of QOL.

As in QOL, it can be argued that the meaning of cancer survivorship is highly individualistic and therefore it may not be appropriate to use a single definition. There is increased recognition that cancer survivorship can include significant shifts in personal identity and beliefs, and may change the salience of different aspects of individuals' lives, often resulting in the adoption of a post-cancer illness-related survivor identity. In contrast, some cancer patients do not identify with this term and feel that is not appropriate for their experiences. Many feel they do not merit this title or reject it due to concern regarding cancer recurrence, which, for some, may indeed become a reality. To date there is no literature investigating what cancer survivorship means to colorectal cancer patients who have undergone resection for liver metastases, and whether they identify with this term. Understanding what survivorship means to this patient group, and whether they feel this to appropriately capture their experiences, will not only provide original insight into this population group, but may also give additional insight into their QOL. Additionally, the appropriateness and meaning of survivorship may be of particular relevance to this group due to the unfavourable survival rates. As cancer survivorship can have a significant impact on individual identity and life views, it may also have an impact on changes in QOL and what QOL means to cancer survivors. Understanding survivorship experiences in this group may provide further insight into how the meaning of QOL for CRC patients with liver metastases is formed and how this may change over time. As this is a new area of enquiry within this patient group, pre-structured quantitative measures do not offer the flexibility to fully explore this topic. In order to explore individual experiences, a qualitative approach is needed.

Therefore the aim of this study is to investigate the impact of CRC with liver metastases on long-term quality of life and survivorship experiences, using a semi-structured qualitative approach, and in view of the limitations of quantitative measures in fully capturing QOL data, to consider the relevance of the widely used EORTC questionnaires to this population.

# This investigation

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Within the University of Bristol a longitudinal prospective cohort study was carried out investigating patient-reported outcomes after hepatic resection of CRC metastases. This study focused on investigating HRQL in consecutive patients selected for hepatic resection following a primary diagnosis of CRC. Patients completed the EORTC QLQ-C30 and LCM21 questionnaires (Fayers & Bottomly, 2002; Kavadas et al., 2003) with outcomes collected at up to 5 years post-surgery (full details of the study can be found in the methods section).

During my involvement in data collection as part of this study and through further reading around QOL, I became curious as to whether these questionnaires were capturing the full patient experience. I felt that further work was needed to understand the experiences of long-term cancer survivors. If QOL is a subjective experience and could change over time, it was unclear to me how objective measures developed to measure short-term QOL would give an accurate or adequately detailed picture of long-term survivor experiences. I believed that qualitative enquiry with this patient group was needed and could provide greater insight into a much neglected area of investigation. I approached the Primary Investigator of the study (JR), who was also my work line manager at this time, as to whether I could carry out a qualitative piece of work with the patients for my Doctoral Thesis. He was supportive of this suggestion and agreed that it would add insight and understanding to the current work and state of knowledge. In addition, JR was keen to develop his qualitative skills and therefore requested to be involved with the interview schedule development and conducting a small number of interviews.

During the development of the quantitative protocol, JR had speculatively included a nested qualitative study. This had not received funding and therefore had not been taken any further. However, this meant that NHS ethical approval had already been granted for qualitative enquiry with this patient group prior to my involvement.

I discussed my thoughts with JR and explained my scepticism that current quantitative measures were able to fully tap into patient experiences. In line with these discussions and due to the current debates on QOL, it felt that an exploration into how the quantitative results reflected patient experience would be beneficial. As I did not want to limit discussion around QOL with the participants, or narrow their focus, it was agreed that this exploration could be included in the proposed interviews, but that it should come at the end of the interview schedule. Rather than define quality of life in any particular way, the scheduled was developed with broad questions asking about the impact the cancer and treatment had had on patients' lives. Later participants

were asked if they felt their experiences had affected their quality of life. No definition was given to the participants and they were free to interpret QOL as what it meant to them. At the end of the interview participants were then given an overview of the EORTC HRQL questionnaire and asked to comment on these specific areas.

During my reading around QOL and the changes that can occur following cancer, I became increasingly interested in cancer survivorship identity. Just as in QOL, cancer survivorship is highly individualistic, and the meaning of the term differs between individuals. Increasing parallels between the two concepts can be drawn through an exploration of how the salience of different aspects of individuals' lives change over time and as a result of cancer. In QOL the focus is on how the changing salience of these aspects contributes to individuals' perceived satisfaction with life, whereas in survivorship the focus is on how these changes affect an individual's self-concept. It seemed clear that an individual's identity has a key bearing on how the person perceives life and their level of satisfaction with life. If cancer results in a significant shift in an individual's self-concept, then it would follow that their views on life will also change. Exploring cancer survivorship offers an additional lens with which to explore changes to QOL in long-term cancer survivors. Therefore, I chose to include a section within the interviews focused on survivorship. Firstly asking whether participants identified with this term, and secondly, what this meant to them.

Further details on the interview schedule are given in the method section.

# Aims and objectives

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## **Aims**

1. To explore the impact of CRC on long-term quality of life in cancer survivors at least 5 years post-surgery using qualitative interviews
2. To explore survivorship experiences in CRC survivors at least 5 years post-surgery using qualitative interviews
3. To explore the relevance of the EORTC QLQ-C30 and LMC21 questionnaire domains to this population

## **Objectives**

Carry out qualitative interviews with colorectal cancer survivors to:

1. Explore quality of life issues that have arisen post-surgery
2. Explore survivorship experiences
3. Explore participant views on the current EORTC questionnaire topics
4. Explore additional quality of life issues not currently being addressed in the EORTC questionnaires

# Methods

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## Approach taken

As previous in-depth research in this area at the level of the individual is lacking, a flexible and exploratory approach to the collection of data was adopted. Qualitative enquiry offers the benefits of flexibility in that this approach allows the researcher to gain insight into individual perspectives and investigate areas that may not have been previously considered. As the long-term impact of CRC with liver metastases has largely been investigated through quantitative means, and with a focus on HRQL, it is possible that current research is missing important aspects of patient experience. Qualitative enquiry offers the opportunity to explore new areas elicited directly from the participant, and also to further explore issues that are already known.

Qualitative methods also allow for discussion of sensitive and personal issues. A skilled qualitative researcher is able to build rapport with a participant and may elicit information that may not be disclosed through quantitative questionnaire work. For example, QOL questionnaire data on sex life often had a high proportion of missing data (e.g. Rauch, Miny, Conroy, Neyton & Guilrmin, 2004). During qualitative interviews the researcher is able to build up to questions around this topic and help participants feel more comfortable disclosing personal information and discussing these issues.

Qualitative research can be broadly divided into two main categories; experiential and critical (Braun & Clarke, 2013). Experiential research seeks to look at meanings, views, perspectives and practices, with a key focus on participants' interpretations. This type of qualitative research is driven by a desire to understand individuals' experiences and perspectives. On the other hand, critical qualitative research does not take meaning at face value but seeks to look at what meanings represent, and focuses on the researchers interpretations of the data rather than the data itself. The purpose of this research is to explore and understand the experiences of long-term survivors of CRC with liver metastases. Due to the focus on the participants' experiences and perspectives, this project can be categorised as experiential qualitative research.

## Theoretical standpoint

A key aspect of defining a qualitative approach is the ontological and epistemological stand point taken by the researcher. Ontology and epistemology respectively refer to the nature of reality and knowledge, or in other words, what is meaningful knowledge and how can we seek to know it. An important part of the qualitative process is ensuring a good fit between the ontological

underpinnings and the method of enquiry (Snape & Spencer, 2003; Bracken, 2010). This ensures clarity in *what* a researcher is seeking to know or understand, and *how* the researcher believes this can be known.

In qualitative research there is a wide variation in researchers' views of what constitutes reality, ranging from a realist approach where reality is entirely independent of human interaction and therefore wholly knowable, to a relativist approach where reality is entirely constructed through human interpretation. This research takes a critical realist position (Bhaskar, 1989). This perspective acknowledges that whilst a concrete reality does exist, individuals' perceptions of this reality are subjective and socially influenced, and can vary over time. Critical realism holds that although external reality provides a foundation for knowledge, it is socially influenced and relies on individual interpretation, both from the research participants and the researcher themselves. Further discussion of the researcher's position is included in the reflective chapter.

In addition to defining what is meant by reality, it is also important to be clear on how the researcher believes this reality can be accessed and known, i.e. the epistemology. Epistemological standpoints fall along a similar spectrum to realist and relativist ontologies, ranging from positivist to constructionist (Flick, 2009). Positivism posits that knowledge is based on objective and unbiased collection of data, and that there is only one version of 'the truth'. At the other end of the spectrum constructionism argues that knowledge is entirely subjective and is created by the meanings we as individuals ascribe to it. As meaning can change over time according to social and cultural contexts, there is no one 'truth', but instead many interpretations of reality or 'knowledges' (Braun & Clarke, 2013).

This research takes a contextualist approach. A contextualist approach does not assume a single reality but acknowledges the ways in which individuals create meaning behind their experiences but also the ways in which broader social context impinges on those meanings (Braun & Clarke, 2006). This approach is concerned with understanding individuals' experiences within a certain context.

As the purpose of this research is to explore individuals' experiences of CRC with liver metastases, a critical realist, contextualist approach was deemed appropriate. This approach acknowledges the external reality of having cancer, but also recognises that individuals perceive and experience this in a subjective way.

## Data collection

In-depth semi-structured face to face interviews were chosen as they allowed the research to focus on the broad areas of quality of life and survivorship, whilst still allowing the researcher to be responsive to other relevant issues that were spontaneously raised by the interviewee. As well as facilitating change in the focus of the interview in line with the participants' response, the semi-structured questions also allow for the use of probes to achieve a fuller understanding of the participants meaning and a greater depth of answers. The flexible nature of this work allows the researcher to frame questions differently for individual participants and use language that they are more familiar/comfortable with. Given that one of the aims of this research is to explore areas of quality of life which may not be currently addressed in the EORTC questionnaire, this flexibility is particularly important. If a quantitative method had been used it would not have allowed for this flexibility in approach, the exploration of previously unconsidered areas, or the use of probes. Therefore, a qualitative semi-structured approach was deemed the most appropriate method of investigation.

One to one interviews allow the interviewer to explore individual differences in experience in detail, which may not have been possible in a focus group environment. Given that the bodily location and nature of the symptoms and consequences of CRC many of the issues faced by these patients, such as sexual function, are highly personal and sensitive, it was thought that one to one interviews would allow for greater rapport and openness between the participant and researcher.

## Interview design

A semi-structured interview schedule was designed based on an extensive review of the current QOL literature. The schedule contained four sections focusing on first diagnosis and treatment, impact on QOL, survivorship experiences, and views of the EORTC questionnaires (for a full interview schedule see appendix 3). Due to the sensitive nature of this investigation, and to further develop qualitative expertise, an experienced researcher was consulted for advice on how best to approach these topics.

The first section allowed participants to get used to answering questions and expressing their views. This was particular importance for anxious or nervous participants as it helped to put them at ease and build rapport. They were first asked to introduce themselves and then talk about how they were diagnosed and to describe the treatment they received. This section also included questions about how follow-up appointments affected them. In addition to providing a straightforward introduction to the interview, understanding their initial diagnosis and treatment gave a full picture of their cancer journey.



The second section of the interview related to QOL. This began with questions regarding the impact of the cancer on a practical level, and then asked about how their experiences had affected, and continued to affect, their QOL in a broader sense. This included practical, emotional, social and physical impact. If the participant was in a romantic relationship, or had been during their cancer diagnosis and recovery, they were asked if their experiences had impacted on this. If the participant brought up areas or issues which the interviewer had not asked about or considered, the interviewer pursued this line of questioning and asked relevant follow-up questions.

Section three focused on survivorship and identity. This covered whether the participants viewed themselves as a 'survivor' and what this meant to them, whether the cancer had changed their views about themselves, and if their priorities in life had changed. Literature on cancer survivorship suggests that experiencing cancer can change the way individuals view themselves in relation to the world, or their perceptions of their identity, and may therefore also affect quality of life (Tedeschi, Park & Calhoun, 1998). The EORTC QOL questionnaire given to these participants does not explore this and therefore it was felt to be an additional area of important to include in the interview schedule.

The final section of the interview focused on the domains included within the EORTC QOL questionnaire. This had been sent to participants at intervals over a period of 5 years and contained both a general and disease specific section. Participants were given a list of topics included in the questionnaire and asked if they felt anything was missing, if it covered all the issues/experiences that had been important to them, or if they felt anything was irrelevant. The researcher also explained that this questionnaire was developed to measure short-term QOL and asked the participants to consider if the same issues had been relevant throughout their cancer journey from diagnosis until the present, if any were relevant/irrelevant at different time points, and if there were issues not included which would be more relevant to ask about as a long-term survivor. Finally the interviewer discussed how the questionnaire topics compared with the issues the participant had talked about during the interview. See appendix 3 for full interview schedule.

## **Materials**

An information sheet and consent form were designed in line with NHS guidelines, and were approved by NHS ethics (see appendix 4). The information sheet outlined the purpose of the research and why participants had been invited to take part. It assured them that all data obtained in the interview were completely confidential and anonymous, and that in the event of

publication the participants would not be identifiable. Participants were informed that their participation in the study was completely voluntary and that they could withdraw from the study at any time and for any reason. The information sheet was sent to participants prior to the interview. They were given a second opportunity to read it and ask any questions before the start of the interview. Before starting the interview participants were told that they did not have to answer any questions that made them feel uncomfortable and that they could terminate the interview at any point if they did not wish to continue.

## Participants

### Identification of participants from an existing cohort

A quantitative study investigating long-term HRQL in CRC patients with liver metastases has been carried out at The University of Bristol within The Centre for Surgical Research. The aim of this study was to measure the impact of liver resection for CRC metastases on HRQL using quantitative questionnaire data from the European Organisation for Research and Treatment of Cancer (EORTC) core questionnaire, EORTC Quality of Life Questionnaire (QLQ) –C30, and a disease specific questionnaire for colorectal liver metastases, the EORTC QLQ-LMC21 (Fayers & Bottomly, 2002; Kavadas et al., 2003). The EORTC QLQ-C30 is one of the mostly widely used measures of HRQL in cancer patients and assesses functional domains and symptoms that commonly occur across cancer patients. The EORTC QLQ-LMC21 is a disease specific questionnaire validated for individuals with colorectal hepatic metastases. It contains four scales assessing nutritional problems, activity/vigour problems, pain, and emotional functioning, and nine single-symptom items. For a full copy of both questionnaires see appendix 1.

This study recruited patients between April 2004 and May 2007 who were undergoing standard resection of liver metastases from CRC from two sites in the UK; University Hospitals Bristol NHS Foundation Trust and Basingstoke and North Hampshire NHS Foundation Trust. Patients were eligible for inclusion in the study if they had a previous diagnosis of colonic or rectal primary cancer with hepatic metastases, and were able to understand and complete the chosen questionnaires with minimal assistance. Patients with a concurrent malignancy (except basal-cell carcinoma of the skin), and those taking part in another questionnaire study that would interfere with the protocol were excluded. Overall, 241 were recruited into the study with 107 (46%) of original cohort still alive at 5 years post-surgery. Quantitative questionnaire data were collected at baseline at least 4 weeks prior to treatment, and then at 3, 6 and 12 months after surgery, with a final long-term follow-up questionnaire at 5 years post-surgery. At the 5-year follow-up patients were asked if they would be interested in participating in an interview based qualitative study

exploring the impact of CRC with liver metastases on quality of life. Patients who expressed an interest were sent an invitation letter inviting them to take part in an interview, a patient information sheet explaining the purpose of the interview and study, and a reply slip. Those patients who returned a reply slip were then contacted by telephone or email to organise a suitable time to conduct the interview (participant documents can be seen in appendix 4). In total 26 patients were contacted through an initial invitation letter and 15 were interviewed. The 11 patients not interviewed did not reply to the invitation letter or to a follow-up letter.

### Inclusion/exclusion criteria

Participants were identified from an existing quantitative study cohort and were at least 5 years post-surgery for CRC liver metastases. Inclusion criteria were that they were able to speak and understand English and were over the age of 18. No geographical exclusion was applied.

### Sample size

Determining sample size for qualitative research is a complex issue that must take into consideration not only what the researcher wants to know, but also how they seek to know it. Rather than a focus on generalizability and power, as in quantitative research, qualitative research is more concerned with the scope of the study and the quality and depth of the data (Braun & Clarke, 2013). The key issue for sample size in qualitative research is that it must be appropriate for the research question and theoretical approach of the study. For example, an in-depth case study may only focus on one participant, or a secondary analysis of printed materials or media may include over 100 different sources. Following this approach, an adequate sample size can be thought of as one that gives enough data, both in quality and depth, in order to answer the research question (Marshall, 1996).

This study is aimed at exploring participant experience of CRC with liver metastases in relation to QOL and survivorship issues using one to one interviews. Following guidelines from Braun and Clarke (2013), exploring experiences through one to one interviewing requires a moderate sample size of between 10-20 interviews. This allows the researcher to explore patterns across the data set whilst still maintaining a focus on individual experience. In the first instance 10 interviews were carried out, however, following the progression viva and in consultation with senior qualitative expert, it was felt that this sample size was not sufficient due to a number of considerations. Firstly, a small number of interviews were carried out by a second researcher with very little qualitative experience and from a medical background, as such it was likely that these interviews would be less detailed and have a greater focus on medical issues. In addition, it was thought that some of the issues around sex life and personal experiences were likely to be highly gendered and at this time only 2 female participants had been recruited (for a full discussion on

interviewer-participant relationship and gender differences, see reflective chapter). The recommendation was to carry out additional interviews with a focus on recruiting more female participants. Following this discussion, 10 further invitations were sent to participants. Purposive sampling was used to recruit additional female participants with invitations being sent to all women who had previously stated they would be interested in taking part. Five additional participants agreed to take part in an interview, 3 women and 2 men. This gave a total sample size of 15 interviews, which was considered appropriate for both the research question and method of enquiry (Baker & Edwards, 2012; Braun & Clarke, 2013). A descriptive recruitment table can be seen in appendix 2.

## **Procedure**

Interviews were conducted using the guidelines of Rubin and Rubin (2005) and Legard, Keegan & Ward, (2003). This recommends starting with a warm up section and building up to more personal questions. First the purpose of the research was explained to the participant and they were told that all information was completely confidential and anonymous. They were told that participation was voluntary and they could withdraw from the study at any time and for any reason, and could stop the interview at any point. They were given the opportunity to ask any questions they might have, and finally asked to sign a consent form.

Interviews lasted between 60 and 114 minutes, with most lasting approximately 1 hour. Interviews were digitally recorded and then transcribed word for word onto a computer. Audio files and transcripts were stored on password-protected computers, to which only the project team had access. Two researchers carried out the interviews. Interviewer 1, KW, was the qualitative project lead. KW had experience of both qualitative work and conducting in-depth interviews on sensitive issues. Interviewer 2, JR, was the quantitative project lead and line manager for interviewer 1, KW. JR had limited experience of qualitative research and had not carried out any interviews prior to this study. Overall, JR conducted 3 interviews and KW conducted 12 interviews. Interviewer 2, JR, was not involved in the analysis stage of this project. Further discussion of the contribution of the interviewers can be found in the reflective chapter.

## **Analysis**

As the main aims of this research are exploratory, a descriptive analysis was deemed most appropriate. Due to the critical realist and contextualist approach, both thematic analysis (TA) and interpretative phenomenological analysis (IPA) were considered.

TA is a flexible descriptive method that seeks to identify themes and patterns of meaning across the dataset. The aim of TA is to provide a detailed account of the overall dataset, by describing participants' experiences and the similarities and differences within the data set as a whole, and how this is situated within the wider sociocultural context. However, due to its focus on description it has been criticised for lacking interpretative power and for losing the individual nuances of participants' stories (Joffe & Yardley, 2004). IPA also identifies patterns across the data, but instead of providing an account of the dataset as a whole, the focus of IPA is far more individualistic and interested in how people make sense of their own lived experiences. With this approach, the emphasis is on how individuals construct and understand everyday experiences of reality, with little attention given to broader social context. This approach can provide detailed insights into individual experience, and how these experiences fit within the dataset as a whole, however due to this dual focus it can lack the overall descriptive narrative of TA, and provides little understanding of how these experiences are situated within the wider sociocultural context.

Although both IPA and TA could provide interesting and valuable insights into the lives of CRC cancer survivors, given that the aim of this project is to explore and describe what these experiences are rather than a detailed exploration of individual perceptions, TA was chosen as the most appropriate analytical method.

TA has several variations and can be driven by existing theory (theoretical TA) or by the data (inductive TA) (Braun & Clarke, 2013). As very little is known about this topic area and one of the aims of this research is to explore the relevance of the EORTC questionnaires to this population and additional areas which may be important to consider, theoretical TA is not appropriate as it uses a top down approach driven by pre-existing theory. Inductive TA allows the researcher to take an active role in analysis and to report themes in the data driven by an overall topic area, but still allows for the exploration of themes which may not have been previously considered. Therefore, inductive TA was chosen.

Inductive TA was conducted following the guidelines of Braun and Clarke (2006) and using the NVivo software package. Audio files were professionally transcribed by an external company, UK Transcription, however in order to personally reflect on interview technique, KW transcribed the first interview conducted.

The first stage of analysis process is becoming familiar with the data and making initial notes. In order to do this KW read and reread each transcript several times, whilst making initial notes and highlighting areas of interest. The second phase was the generation of codes across the dataset. Although the aims of this research were to investigate QOL and survivorship experiences, as an

inductive approach was used the initial notes and coding were guided by the data and was not limited to these areas. The second phase of analysis was the complete coding of the whole dataset. In this process, interesting features of the data were broken down into meaningful segments and coded using a word or short phrase. This process was conducted for all transcripts with the data for each code being collated using NVivo. Once all the transcripts had been coded, the individual codes were reviewed and placed into clusters guided by how they related to each other.

Overall 42 clusters were created. Clusters were then reviewed against the study aims and assessed for relevance to long-term QOL and survivorship experiences; clusters that were not relevant to the study aims were not taken further in the analysis process. For example, clusters relating to treatment experiences or short-term symptoms were discarded as they referred to short-term experiences that were no longer relevant to the participants as long-term cancer survivors. A full list of clusters can be seen in appendix 5. Final clusters were organised into themes and subthemes. During process of organising the themes and subthemes, a fellow qualitative researcher with experience of research in sensitive topics was consulted. The purpose of this discussion was not to provide the results with a more valid organisation of themes, or to claim that they represent a singular explanation of participant experiences, but rather to offer further insight and dialogue regarding the complexity and understanding of the issues (Tracey, 2010).

Overall 3 main themes and 11 subthemes were identified. A full table of themes is presented in the results section.

## **Ensuring quality and rigour in qualitative research**

Ensuring quality in qualitative research can be challenging given the variation in criteria for what constitutes 'high quality' research. Given the subjective nature of qualitative research, quantitative standards such as reliability, validity, generalisability and lack of bias are not appropriate. Qualitative research recognises that the researcher is an active agent in the research process. Researchers bring their own experiences, belief, assumptions and person to the research, and as such the data and knowledge produced will reflect this. In addition, the fact that it is situated within a range of different epistemological and ontological approaches has meant that agreement on a universal set of quality criteria has been significant challenge. Many would argue that quality criteria must be tied to specific theories or standpoints (Cunliffe, 2011; Denzin, 2008; Ellingson, 2008; Golafshani, 2003; Guba & Lincoln, 2005), and that to work towards a universal model denies the multiplicity and subjectivity of qualitative work.

For applied health research this is particularly problematic, for if the researchers seek to influence practice, questions will be asked about the trustworthiness of the results. Health policy makers and clinicians following evidence-based practice guidelines will want to feel the research is sufficiently trustworthy on which to base decisions on. Whilst there is increasing acknowledgement from the health service that 'lay' perspectives and multidisciplinary models of health are important in planning service provision (Stationary office, 2000; Department for Health, 2004), this presents an even greater need to demonstrate quality and rigour in qualitative work that can be understood by those not familiar with qualitative language and advanced theoretical underpinnings.

More recent work has suggested that it is possible to provide a core set of trans-theoretical standards which differentiate between the end goals of good quality qualitative research and the means used to get there. This provides a structure for examining the quality and presentation of the end results, whilst still recognising the complex differences in how researchers may arrive at these results (Tracey, 2010). This research has chosen to follow the 'eight 'big tent'' criteria, as published by Tracey (2010). This approach seeks to provide a universal model for quality in qualitative research, including both how the research is carried out, and how it is presented.

Tracey suggests eight key markers for quality in qualitative work (a full table can be seen in appendix 6):

- a) worthy topic
- b) rich rigour
- c) sincerity
- d) credibility
- e) resonance
- f) significant contribution
- g) ethics
- h) meaningful coherence

At the core of these criteria is a focus on transparency in approach and method, with the results firmly rooted in the data. The researcher should offer a clear account of the steps of analysis, and engage in open and honest self-reflexivity. Through the process of self-reflexivity, the researcher recognises their role in the data collection and analysis process, and offers an open discussion regarding their strengths and weaknesses (Richardson, 2000; Tracey 2010). In order to achieve this in the current study, a reflective chapter is included which offers a reflexive account of the project.

Tracey also discusses the importance of 'credibility' in research. This refers to the trustworthiness and plausibility of the research findings. Credibility can be achieved through a number of different practices. Firstly, the results should offer a full and detailed description of the data, with themes clearly illustrated by appropriate quotes from the participants. The complexity and contradictory nature of participant accounts should not be ignored. The practices of triangulation and crystallisation can also add to the credibility of research. Both these practices suggest that qualitative enquiry can benefit from multiple types of enquiry, data sources, and research involvement. Rather than confirming that these different methods of enquiry or researcher involvement provide the same conclusion, this approach allows different facets and aspects of participant experience to be explored, and may deepen understanding. Within the current project, crystallisation and triangulation using different sources of qualitative data were not possible, however the organisation of the themes and subthemes were discussed at length with another qualitative researcher. This offered greater insight and discussion around the complexity and understanding of the issues, and provided opportunity to consider different organisations of themes (Tracey, 2010).

## **Ethics**

Full NHS ethical approval was granted for this study. Research sponsorship and insurance were granted by the University of Bristol. Participants were provided with NHS approved information sheets prior to the interview. Participants were given the opportunity to ask any questions regarding the study, interview process, anonymity protection, study withdrawal, and any additional issues. If participants were happy to proceed with the interview they were asked to sign duplicate consent forms, one copy retained for themselves and one copy for the researcher's records.

As interviews were planned to take place in participants' homes, a researcher protection protocol was put in place. Prior to the interview a named contact was given details of the interview location, time, participant name, and a contact phone number for the address. The researcher conducting the interview sent a text message to the contact on arrival at the property, and on completion of the interview. It was agreed that if no contact had been made 2.5 hours after arrival, then the contact would call the address phone number. A code was established in order for the researcher to convey safety or danger without alerting the participants.

There were no foreseeable ethical issues of note; however given the sensitive nature of the interview topic it was important to be aware that the interviews might raise emotional or distressing issues about participants' experiences. Participants were told that they could stop the



interview at any time and did not have to answer any questions they felt uncomfortable with. If a participant became distressed then the interviewer asked if they were happy to continue or would like to stop the interview. The interviewer also had the ability to provide the participant with contact details for cancer support services and helplines.

# Reflective chapter

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*Data collection can be an intense experience, especially if the topic that one has chosen has to do with the illness experience or other stressful human experiences. The stories that the qualitative researcher obtains in interviews will be stories of intense suffering, social injustice, or other things that will shock the researcher (Morse & Field, 1995, p.78)*

As previously discussed, a key aspect to ensuring quality and rigour in qualitative research is the practice of self-reflection (Richardson, 2000; Tracey 2010). Not only does this contribute to transparency of practice, but also offers the researcher an opportunity to further develop their skills and reflect on areas for future improvement. As this chapter is focused on the researcher experience, it will be written in the first person.

It is widely recognised that the researcher is an active agent in the research process. We as researchers are responsible for setting the tone of the interview, following up on participant comments, and asking the questions. It would be naïve and perhaps arrogant to imagine that one can remain completely objective throughout this process, that one's own experiences and beliefs have no impact on the interview. Researchers and participants jointly produce knowledge and interpretation of data, not only through collection and analysis, but also through the construction of a researcher-participant dialogue and narrative (Manderson, Bennett & Andajani-Sutjahjo, 2006). Being able to honestly and openly discuss one's role within the research process is a core attribute in ensuring good quality research; not only the good and positive aspects, but also what didn't work well, and the shortcomings. In order to do this, I will firstly provide an overview of the researchers involved, their backgrounds and standpoints, and then discuss two of the main challenges I encountered during this project.

## **The interviewers: background and experience**

Two interviewers were involved in developing the interview topic guide and conducting the interviews; myself, and my work line-manager JR.

### **JR**

JR worked as an Academic Clinical Lecturer and hepatobiliary surgeon. JR had a background interest in this work and had been running a quantitative project exploring QOL in the same patient population. A surgeon by training, he had a vested interest in the outcomes after surgery, in particular the physical symptoms. JR was experienced in talking to patients about sensitive

issues within a medical setting, and in talking to a wide range of people from different backgrounds. However, he had never conducted qualitative research before and had very minimal knowledge regarding the theoretical underpinnings and standpoints that qualitative work contains. He had attended a two-day short course offering a basic introduction to qualitative research.

Overall JR conducted 3 interviews. When reading through these transcripts it became very clear that the focus of questioning and areas that JR followed up were predominantly medical. There was little focus on emotional and psychological aspects of the patients' experience, or discussion around the psychosocial issues. The interviews were shorter and aligned very closely to the initial topic guide. I feel this may firstly be due to this background training, and secondly his inexperience in conducting in-depth qualitative work. Transcripts of researchers just starting out in qualitative work do tend to be more linear and stick closely to the initial topic guide. Once researchers become more experienced, interviews tend to become messier and longer. The topic guide is used less and serves more as a starting off point, with many other areas and thoughts being explored.

I was frustrated by the medical approach to the interviews. At certain points during the interviews extremely interesting or insightful comments from the participants were not followed up or probed. Whereas any mention of medical symptoms or side effects were discussed in great detail. Due to the existing work relationship between JR and myself, in particular the power balance and hierarchy implication, I was unsure how to approach these issues or if this would be appropriate. JR was keen to learn about qualitative research and develop his skills, yet it was challenging for me to provide constructive criticism or highlight points of learning, due to his role as my line manager. After reflecting on the implications of his approach for the current project, I felt that although this focus and view point was different from my own, it did provide an alternative and additional insight into participants' lives. I believe that an open and honest discussion between us as researchers would have been beneficial and allowed us to further understand the other's perspective. In future work I feel I would be more confident in initiating this, and being clear from the outset that this is key part of the data collection and analysis process.

## **KW**

Following the completion of my MSc in Health Psychology, I have worked in a number of different University research departments and have developed an interest in stigmatising health conditions and conducting research on sensitive topics. During this time I have gained a wide range of experience in conducting qualitative work with different populations and on a variety of applied

health areas. This includes childhood obesity, young people's attitudes towards visible difference, prisoner identity and body image, and the impact of continence problems on young people. As such I have developed expertise in carrying out semi-structured interviews on sensitive and highly personal issues, and have worked hard to be able to develop rapport with participants to put them at ease and allow them to discuss potentially distressing topics.

Understanding and beliefs about different health conditions, such as cancer, will of course have an impact on the interview process. Preconceptions about what this illness means for people or what having cancer is like will influence the types of questions asked and which comments or areas of thought are probed further. For many researchers, their views and experiences of cancer may be entirely theoretical or within a work context. For me, this was not the case. Prior to and during this project I had two first hand experiences of cancer. Firstly, my mother was diagnosed with cervical cancer whilst she was pregnant with me. Whilst I have no direct experience of this, it is something that she has been very open about and we have frequently discussed. Her decision to go through with the pregnancy was, at the time, very controversial and went against the majority of medical opinion. This early acknowledgment of cancer and its presence in my life was not something I had overly reflected on until this project. Anecdotally, my understanding of cancer was one of survival. Of beating the odds and having no regrets. That if you fight hard enough and think positively, you'll be ok. Both my mother's early diagnosis of cancer due to her pregnancy and her decision to continue with the pregnancy, has meant both her life and my own are tied to cancer in a way which most people's lives are not. For me, cancer was not a taboo word, something to be whispered or feared. If anything I had been quite blasé in discussing it.

My second experience of cancer was a stark contrast. During the write up of this project, a close friend was diagnosed with what we believe to be metastatic stomach cancer. Despite everyone's hopes that her young age would prove her saviour, the disease was too advanced and devastatingly she passed away within 2 weeks of her diagnosis. Although the analysis of my data was complete at this point, this experience has without doubt affected my thoughts and feelings during the write up. Reflections on what participants have said and what their partners have said have been given another dimension. The anger and unfairness many participants expressed is now part of my own experience. For several weeks after she died, I felt unable to continue with my work for fear of how I would feel about it. My concern was that it would prove too painful, and that my experiences would cloud my interpretation and presentation of the results.

What I, myself, bring to this work and the lens through which I view it, are forever bound to my own experiences, thoughts and feelings. To be fully reflexive and honest about my role as a

qualitative researcher, it is vital to acknowledge and to be open about my own experiences of cancer. To ignore or marginalise this would be, I feel, untrue to my work.

## **Phenomenological standpoint**

During my early career as a qualitative researcher, I struggled to identify my phenomenological standpoint. Although I feel I can claim a good understanding of the different approaches and beliefs that qualitative researchers can hold, understanding where I fitted along this continuum proved more challenging than I expected. I started my education by undertaking a BSc in Applied Psychology and Sociology. The inclusion of Sociology in my training and formation of my views and beliefs about the world has, I believe, been a key determinant and influencing factor in my research work and approach to qualitative work. My views on the socially constructed nature of societal norms and the continual balance of structure and agency have been at the core of the development of my standpoint.

Through reading extensively about the different theoretical approaches to qualitative work, I feel that the view which most represents my own is that of the critical realist. As previously discussed, this perspective acknowledges that whilst a concrete reality does exist, individuals' perceptions of this reality are subjective and socially influenced, and can vary over time. Critical realism holds that although external reality provides a foundation for knowledge, it is socially influenced and relies on individual interpretation, both from the research participants and the researcher themselves.

## **Interviewer-participant relationship**

The impact and importance of the researcher and participant biography has long been recognised in qualitative research (Broom, Hand & Tovey, 2009). The nature of the qualitative interview is such that the relationship between interviewer and interviewee is central to the process. Just as in any human interaction, cultural and social factors such as age, class, gender, ethnicity and sexuality will shape interactions both in terms of constraints and also as a facilitating factor. In qualitative work, it is of particular importance that the situatedness of the data, and the factors involved in constructing both the dialogue and interpersonal dynamics of the interview are recognised (Broom et al., 2009).

Within the literature the influence of interviewer and participant gender has received the most attention. Rapport building during interviews is often based on finding shared understandings and commonalities, and thereby jointly constructing the narrative of the interview. Gender can have a profound impact of how these narratives are shaped and how both the interviewer and

participant present themselves and their stories. Many researchers assume that same-sex interviewing is the ideal preference and will result in the highest rapport and understanding (e.g. Imber, 1986, Grief & Pabst, 1988). However it is not clear if this is always the case. Later work has suggested that gender congruence can both facilitate reciprocity, but also foster performance of idealised or stereotypical gender norms (Williams & Hiekes, 1993). Man-man interviews often result in enhanced male overtures about manliness, sexual behaviour, masculinity, and dominance. This may be due to the need to reinforce status and vie for power within the research relationship, or form part of male bonding rituals. However, it has also been suggested that the use of hyper-masculinity may be a method of covering up key issues faced by men which threaten their self-esteem and male identity. This type of behaviour is highlighted by Broom (2004) in work looking at impotence and incontinence after prostate cancer.

Women interviewing men is common practice in the field of qualitative research. The preference of men for a female interviewer may be due to the fact that men are more comfortable engaging in personal discussions with women rather than with other men (Williams & Heikes, 1993). Within Western culture, it is likely that the majority of heterosexual male personal disclosure will occur with a female partner. Men have been found to perceive women as more naturally interested in emotional and interpersonal issues and hence feel more inclined to engage in these discussions (Lohan, 2000). Additionally, there is higher societal approval for male-female intimacy and expressions of vulnerability compared to male-male interactions (Rubin, 1976). However the female-male interview can also prove problematic in the reinforcement of traditional gender and power roles within the interview, which situate the female interviewer as a passive member of the interaction whose role is to listen and provide agreement (Arendell, 1997; Winchester, 1996). In McKee and O'Brien's discussion on interviewer-interviewee power relations, they describe how in female-male interviews, male participants often seek to control the interview situation.

During the interviews I was aware that the type and style of dialogue was different when interviewing women and men. Although I interviewed fewer women than men, I found it easier to establish rapport and more quickly turned to deeper emotional and interpersonal discussion with these women. Whether as a result of my own interpretation or as a reality, I felt that women were more comfortable in disclosing personal details of their life to me. Prior to this study I had little experience of interviewing men, aside from a small project with male prisoners. I was therefore nervous at the start of this project that male participants would not want to talk to young female researcher, or that they would feel embarrassed to disclose sensitive information. My nervousness and hesitation may have contributed to my feelings that the male interviews were less fluid and conversational, and sat much more in line with a formal interview dynamic. However over the course of this study my confidence in interviewing men increased. I became

more familiar with the narratives of female-male interviews and different techniques in both reinforcing similarities and accepting differences. I feel this balance between building common ground and recognising differences helped to build rapport and encourage greater participant disclosure.

## Discussing sex

The gender dynamic between interviewer and interviewee is particularly pertinent in discussions around sex. In discussing sex, the significance of gender roles and identity is heightened. The interviewer is acknowledging the participant as a sexual being and engaging in dialogues situated within feminine and masculine narrative. For example, Broom (2004) talked about the tensions experienced between real lived experience and the need or desire to perform idealised constructions of masculinity. By asking about sexual health, function and satisfaction during the interviews, I was not only asking about their personal experience, but also their relationship status, sexuality, and gender constructions.

One of the biggest challenges for researchers discussing sex is to create a comfortable environment that facilitates participants in offering full and frank disclosures about their sex life (Frith, 2000). Talking about sex is not something which most people feel comfortable doing or will spontaneously do within an interview setting. Questions about sex rely wholly on self-report and the volunteering of sensitive and highly intimate information. I would argue this is particularly true of this study population, given their age. The salience of sex and sexual practices, and the acceptance of sex outside of marriage has increased dramatically over the last 50 years. The advent of the Internet and online pornography has meant that general knowledge of sex the variety of sexual practices is higher, and conversations about sex from a young age are much more normal and accepted. For older adults, their views of sex, experiences of sexual education, and access to erotic and sexual stimuli may be very different.

During my previous qualitative work I had conducted interviews on personal topics such as obesity, body image, and prisoner identity, but I had never discussed a participant's sex life as a stand-alone topic. I was particularly nervous about this as most of my previous work had been conducted with women, and the majority of the participants in this study were older men. In preparing for the first interviews I felt quite anxious about getting this right and making participants feel comfortable talking to me about their experiences. I was very aware that if I approached this in the wrong way, it may cause them to shut down or become embarrassed and unwilling to talk.

When I reflected back on these first interviews I was disappointed in myself as I felt that although I had done a good job in making the participants feel comfortable talking about other areas of quality of life, I had not explored the harder to access conversations and topics which would yield richer, more personal and insightful data. In hindsight I believe I found it easy to ask follow-up questions as it was the participant who had first started the discussion, and therefore I knew they were comfortable in talking about this area of their lives. Although it is very important in qualitative work to build trust and rapport with a participant, I also believe that it is my job as a researcher to push beyond the surface conversation and explore issues which may not be so easy to talk about or something that the participants would normally talk about. Whilst I do not claim to have mastered the art of discussing sex in a research setting, I do feel that the old adage of 'practice makes perfect' holds true. In working to become more comfortable talking about these topics myself, participants appeared to be more comfortable and willing to discuss this area of their life. Regarding the current study, I do feel that further probing into how changes to sexual function had affected participant identity and views of a gendered self could have been done. This would have offered further insight into identity changes as a result of cancer, and perhaps the relationship between post-traumatic growth, identity shift, and QOL.

Previous work has also discussed the issues of vulnerability in qualitative interview work. In conducting at home interviews with previously unknown participants, I was putting myself at risk. Whilst we tend to assume that research participants volunteer through a desire to help and to be involved with the project, there is not guarantee that by attending their home the researcher will not be put in a vulnerable or dangerous situation (Lee, 1997). Lee (1997) argues that this risk is heightened in women interviewing men due to the historical evidence of violence against women, and in particular sexual assault. These considerations become even more salient when the interview contains discussions on sex.

During my own interviews, there were occasions when my sense of caution was raised. During one interview in particular which took place in a participant's mobile home, he talked at great length about how his treatment had caused him to experience a heightened sex drive and sexual desires. Although at no point did I feel threatened or at risk, these deeply personal disclosures made me more aware of my position as a young female researcher in an isolated location. Looking back on this I believe the reason behind this situation being more concerning to me compared to other interviews, is that the discussion was around increased sexual power, in contrast to the discussions with other participants relating to the loss of sexual function.



## Participant documentation

As previously discussed, during the development of the quantitative protocol, a nested qualitative study has been speculatively included. This had not received funding and therefore had not been taken any further. However, this meant that NHS ethical approval had already been granted for qualitative enquiry with this patient group prior to my involvement. As part of the ethical approval process, all participant documentation, including materials related to the qualitative study, were designed and submitted to the ethics committee prior to the commencement of the study. The documentation submitted for the qualitative study included an invitation letter, information sheet, and consent form. As these documents were developed at the time of application for ethical approval, I had no involvement in their design or content.

Within the information sheet it was stated that approximately 30 interviews would be carried out. This information is not consistent with current study design and sample size. As these documents were approved by the NHS ethics committee prior to my involvement, it was not possible to amend this information. However, my name was added to the invitation letter in order for participants to be aware of my involvement and be able to identify me when I called to arrange an interview.

# Results

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## Participants

Overall 15 participants were recruited, 10 males and 5 females. Participants were aged between 65 – 85 years old. All were at least 5 years post-surgery and most were approaching 10 years post-surgery. 1 participant had a permanent colostomy bag, 5 had had a reversal, and 9 had never had a bag. 14 patients were white British, and 1 identified as Black-Caribbean. All participants were retired at the time of interview. During the interviews participants were given the option to have their partner or spouse present. If a participant decided they wanted their partner to be present, it was made clear to both individuals that the focus of the interview was on the participant experience. When involving an additional person in the interview process, there is concern that they may become too involved in the interview and the focus of discussion is changed to their own experiences. However during these interviews this was not the case, and in fact the presence of partners provided a positive addition. The majority of partners acted as a supporting presence and rarely contributed to the interview itself. When a partner did contribute it was often to clarify a memory the participant was discussing. In addition, some partners prompted the interviewee to talk about topics they may not have brought up had they been on their own. Often these were sensitive issues such as sex life or emotional experiences. During the interviews 6 participants had their partner present, and 9 did not. Full participant demographics can be seen in table 1.

**Table 1: Participant demographics and interview details**

<b>Participant</b>	<b>Gender</b>	<b>Age</b>	<b>Stoma status</b>	<b>Partner present</b>	<b>Interviewer</b>
P1	Male	66	No stoma	Yes	JR
P2	Female	78	No stoma	No	JR
P3	Female	75	No stoma	No	KW
P4	Male	68	Reversed stoma	Yes	JR
P5	Male	66	Reversed stoma	Yes	KW
P6	Male	72	Stoma	Yes	KW
P7	Male	84	Reversed stoma	No	KW
P8	Male	85	Reversed stoma	Yes	KW
P9	Male	70	No stoma	No	KW
P10	Male	67	No stoma	No	KW
P11	Male	66	No stoma	Yes	KW
P12	Male	66	No stoma	No	KW
P13	Female	69	No stoma	No	KW
P14	Female	78	Reversed stoma	No	KW
P15	Female	65	No stoma	No	KW

## Themes

Overall 3 main themes and 11 subthemes were identified; Cancer and me: establishing a relationship with cancer, Living with cancer, and Aligning the long-term impacts: the person I've become. These themes are presented in a temporal order. The first theme explores the initial stages of dealing with the personal changes participants experienced as a result of their cancer, and their views of cancer itself. The second theme focuses on participants' experiences of living with cancer day to day on a wider societal level, and the coping strategies they used. The final theme discusses the long-term changes that have endured as a result of the cancer. A full summary is provided in table 2.

**Table 2: Summary of main themes and subthemes**

Theme	Subtheme	Code	Subcode
1. Cancer and me: establishing a relationship with cancer	Being a cancer patient	Patient perception	
		Lack of social understanding	
		Cancer community	
	Cancer as 'other'	Fight/battle	
		Survivorship	Lucky / feeling grateful
	Survivorship	Life priorities	
		Mortality	
		Legacy	
		Non-event	
	Understanding and acceptance	Causes	
		Why me	
		Grief and loss	
		Taken away	
2. Living with cancer	Social support	Communication	
		Community and friends	
		Dependency	
		Lack of support	
		Family support	
		Macmillan	
	Mind-set and mental attitude	Partner	
		Keeping going	Keeping active
			Getting on with it
			Goal setting
	Religion/faith/spirituality/beliefs	Keeping positive	
		Humour	
	Life focus	Living in the moment	
Forward planning			
3. Aligning the long-term impacts: the person I've become	Emotional	Anger	
		Conflicting emotions	
		Disappointment	
		Emotional changes	
		Fear	
		Paranoia	
		Sadness and depression	
		Uncertainty and worry	
		Unexplained emotion	
	Physical	Bladder issues	
		Bowel issues	General issues
			Colostomy/stoma
			Travel
		Fatigue and sleep	
		Physical changes	
	Physical limitations		
	Intrapersonal and interpersonal	Empathy and understanding	
		Importance of family	
Giving back			
Romantic relationships			
Social changes			

## Cancer and me: establishing a relationship with cancer

This theme encompasses the relationship participants had with cancer. It examines what being a cancer patient means to them, how they view their cancer, their understanding of 'survivorship' and the impact this has had on them, and finally if and how they have managed to come to terms with having cancer.

### Being a cancer patient

Being a cancer patient focused primarily around the disparity between participants' expectations of what a cancer patient should be like and look like, and their actual lived experience.

Participants talked about how they didn't perceive themselves as someone who was ill or suffering and that that this was at odds with their previous beliefs about what having cancer would be like.

P11

*"What you believe about cancer is that you're suffering through it while you're experiencing it, and apart from a few instances where, historically, I look back and think 'Yes, that was probably because of it', I'm not aware of going through that while I've had the operations and the chemotherapy. That's rather strange."*

*"Well, your image of cancer is of people suffering because of cancer. That's what your image is, isn't it. Of losing weight, of being ill, of being made incapable by it in the course of it...I'm not aware that that happened to me. The operations caused me to be an invalid for a while, and the chemotherapy caused me to be an invalid for a while, but I'm not aware that the cancer caused that, if you understand the logic"*

In addition to participants not viewing themselves as ill or as being a typical cancer patient, some also talked about how their friends or family reinforced this viewpoint. For P6, this was seen as positive:

P6

*P6: "People used to come in and say 'What are you in here for? You don't look ill'.*

*Interviewer: Yes, how did you find that?*

*P6: "It was strange, yes. I didn't worry about it because I thought, 'well if I don't look ill, it's a bonus'.*

This perceptions of not being a typical cancer patient, led to some participants feeling guilty or like a fraud. This become particularly pertinent when they compared themselves to other cancer

patients or people they knew who had also had cancer. P14 talked about her experiences compared to her sister in law:

P14

*“No, I feel – don’t know if it’s of any help but I almost feel like a fraud because I’ve sailed through it, I’ve not been like a lot of people that... One of my sister in laws, she died of cancer, she’s only 62, she couldn’t talk about it. She had cancer, and I said, ‘I’ve been there, done that, if you want to talk, please talk’. No, she wouldn’t talk to anybody about it. I felt helpless, and I felt she would have been better if she had talked about it, but she was a counsellor for the Samaritans, so if she couldn’t talk about...”*

This viewpoint of not aligning with the stereotypes of a typical cancer patient or not seeming to be ill, lead, in some cases, to a lack of social understanding. Participants talked about how their cancer was dismissed or that as they didn’t look unwell or act as if they were suffering, their friends and family did not understand what they were going through.

P1

*“Yes, but some people dismiss it as, ‘There’s nothing in it’”*

For P4 and his wife, this lead to them avoiding certain social situations and becoming more insular:

P4

*“We chose, I think – for example, family members, we felt we couldn’t go and stay overnight because it’s not very nice and you need time for the bathroom, and if the family has got children – so we chose what we did, but we got used to it. I don’t think people totally understood, because when you see somebody – he always looked well, apart from just a bit pale sometimes. You don’t realise all that’s going on under their clothes, do you?”*

Due to the lack of understanding from family and friends, many participants turned to the cancer community. Brought together by shared experience, other cancer patients provided an in-group level of understanding and support that was not always possible to find through their existing social circle. For many, being able to give support to cancer patients who were starting their journey or had just been diagnosed was an important aspect of their experience.

P6

*Wife: “You can tell other people that have had cancer”*

*P6: “Yes, you can tell other people. You can cheer them up a bit by saying ‘Well this is what I’ve had done, because we don’t mind chatting about it’”*

P10

*"I was talking to somebody about a year ago whose wife had died of this, and he was telling me and so on. Then, I get on to talking about what happened to me, and it was really helpful to him that there was somebody else who could understand. Not that his outcome was good, but who saw the situation as he was dealing with her and so on"*

## Cancer as 'Other'

A very prominent message about how participants related to their cancer was the notion of viewing it as an 'Other'. They dissociated the cancer from being a part of themselves, referring to it as a separate entity or foreign body, as an 'it'.

P1

*"It took away a lot of things from me. I lost all my confidence"*

*"It's got no respect for age, whatever. It could be a child...It's doesn't respect anything like that"*

Many saw it as an intruder into their body that could be fought and attacked. They talked about their cancer journey as a battle or a fight and how they were determined not to let the cancer beat them.

P15

*"It was a fight...Of course it was, but we never let it beat us; we were going to get through it right from the beginning"*

P11 talked a lot about the cancer in this way, especially he was asked about how he felt when he was diagnosed with the secondary liver cancer.

P11

*"I don't know it was probably "It's beaten me', yes? 'It's won a battle'"*

Here he describes his thoughts when he was diagnosed with his secondary cancer.

P11

*"Then, when it came back a second time and I got over it, I thought 'Right, there's no way this is going to beat me. We decided, my wife and I what we would do, that I would work until I was 63, and I am going to do that"*

For some, being given the all-clear from the doctor was a sign that the battle over cancer had been won:

P15

*"I've gone successfully through, I've beaten it, if you like"*

For others, although they were now cancer free, the battle would only be over once they died of something other than cancer:

P11

*"I don't believe I've beaten it. I just think I'm ahead on points. That's fine, I think. That's fine. I hope I die of something else though"*

## Survivorship

Survivorship and what this meant to individuals was a big part of their relationship with cancer. As survivors, the legacy that the cancer had left behind was a prolific topic of conversation. Discussions around survivorship centred on the realisation of their own mortality and led participants to reflect on their life and survival.

For some, survivorship was a positive experience to be celebrated and embraced.

P6

*P6: "Well, he said to us, 'There are not too many get through what he's had'"*

*Interviewer: Yes, how does that make you feel?*

*P6: "Great"*

P9 talked about how he felt after surviving his second operation for liver cancer:

P9

*"Oh, I felt fantastic. I really really did, yes. She's one in a million that woman. I thought, 'She's changed my life again now'. She said 'We will send for you and have you in'. Then I went in, and of course I woke up the next day, 'Oh, I'm here. I'm back amongst the living'. I could have died on that table, so I was a bit, yes I felt fantastic I did."*

The most salient and clear message throughout all the interviews was the feeling of being lucky and grateful. When asked about how they felt about surviving their cancer, nearly all the participants talked about being lucky. They didn't feel that surviving was something they had personally achieved, and in many cases went on to express a lack of understanding about why they had survived.

P11

*"I'm lucky. That's what it means. It doesn't mean I'm special, it doesn't mean I've done anything particularly clever or that I've got this unique ability to fight it that no-one else has got. None of that. I haven't discovered the key to it. I'm just lucky. Yes, twenty years ago I would be dead. That's it."*

P07

*"Lucky, lucky me. My brother died of it 18 years ago. He died the year before my wife died. My mother died of it...I must have a different gene from somewhere. I don't know where it's come from"*

For some, this sense of being lucky was tinged with feelings of guilt. This was particularly evident when participants compared themselves to other cancer patients who had not survived. P14 reflected on how she felt about a friend of hers passing away from cancer:

P14

*"I felt guilty, because I'd had all... She said, 'Ooh I didn't know', you know, felt so sorry for me, and hers was just bang, really. The only thing she had said was 'God, people don't half walk fast, I get out of breath' and that was the only thing. Next thing was she was constipated, she couldn't understand it, got pain in her legs, DVTs, first one leg and then the other. Tests – was put through a scanner and bang, that was it. So I did feel – I felt guilty. I thought, why am I still here, and she went just like that?"*

Seeing other patients die from cancer, and having to deal with this possibility themselves forced participants to face their own mortality in a way which they had not done before.

P13

*"He said 'sorry', but I'd got bowel cancer. I can't tell you the feeling my love. I can't tell you. It's terrible. It's like your whole world falling apart. And you relate cancer to death. And that's all I could see when he told me, is death. But I'm still here. Nearly 10 years, and I give thanks. But it's not a good experience."*

P11

*"I've never thought about death. You've probably never thought about it. You don't when you're young. Now, of course, having cancer, you are faced with that bit of mortality."*

*"Coming back to 'Did the cancer change anything?' I don't think it did, but it triggered that thought off in my mind because I faced mortality, which I'd never done before."*



The increased saliency and, for some, fear of death lead many participants to view life differently and make changes to their priorities in life. P4 talked about reevaluating what he was doing with this life and the routines he had slipped into. For him, surviving cancer was a second chance to make changes, to both what he was doing, and his attitude towards life:

P4

*"I suspect it's a – if you do anything, if you are brought up short suddenly, which causes you to think about, 'Oh, what was I doing before?' I think you sort of look at it and think 'Yes I was slipping a bit into sitting on the sofa in front of the telly, and I have been given another change. There I need to grab it'. That's probably the major change."*

*"You go through a very major trauma, where the outcome can be death, and you think, 'Whoa okay. Well, we got through that. Now's the time maybe to change some of the priorities; maybe to be a little more relaxed'. To use a winter sport analogy, when you know you've won the medal, your fourth run down the bob is usually the quickest one, because you're not worried. You just do it. I think perhaps that's the reaction, isn't it?"*

The change in life priorities and how participants viewed life did encompass some contrasts. For some participants, this was an opportunity to appreciate what they already had in life and the increased importance of family and social relationships. For others, although family remained important, there was a renewed focus on making the most of life and enjoying the time they had left.

P3

*"Well yes you value... you value you have um, you value your family, and relationships, and things more, don't you, because of it, because er rather than yearning for expensive holidays and expensive things, it's much um...you value what you've got and who you've got and... much more, because that's much more, people are more important than things"*

P6

*Wife: "Holidays are important to us now"*

*P6: "Yes we do like to have a good holiday now, don't we, we think we'll have a good holiday"*

*Wife: "Yes let's get on and have one, you don't know how much longer..."*

*P6: "So yes that does change"*

*Interviewer: Some things become less important?*

*P6: "I don't know, really. Less important? I don't think so because everything else we carry on with. We've got two sons and they're just as important as ever. I don't think that makes a lot of difference, really. It makes you think – you do things like, say, holidays and*

*that. 'We'll have a good one this year just in case'. Then next year comes around and you think, 'We'll have another good one this year.'*

For the majority of participants, being having cancer and surviving it had been an extremely significant and life changing event, the impact of which had been long-lasting and enduring. However for others, the cancer had seemingly very little impact on them or their lives. One participant likened the experience to that of having a cold:

P7

*Interviewer: Do you view yourself differently since having had the cancer?*

*P7: "No, no...as I say it's like having a cold, as far as I'm concerned"*

P14

*"I just mean that, from your point of view, you're coming to find out how I coped and I suppose, to me, I've just been ill, I've got to get better"*

P9

*"No nothing changed at all. I don't look back on the downside. I just think positive all the time. Even now, today, it doesn't enter my mind. I don't wake up in the mornings thinking 'Well yes, I've had cancer'. It doesn't do it. I just carry on as though I've never, ever had it."*

## **Understanding and acceptance**

For some, the hardest part of their relationship with cancer was accepting what had been lost or taken away as a consequence of their illness. For others, it was a lack of closure, often stemming from not understanding the cause of the cancer.

P1 in particular talked throughout the interview about a sense of loss and grief. He saw his cancer as something which had taken things away from him, again echoing the sense of the cancer as an 'Other'.

P1

*"It took away a lot of things from me. I lost all my confidence. As I say, I lost my job which is a great big thing to me and everything involved with that so I was disappointed, is that right, upset about that."*

His job had played a large part in his identity and social life. Losing the ability to work had been a very significant negative event.

P1

*"I was a local driver on the railway. It was my life, because my father had done it. I love the job. When people say, 'I hate going to work', I love going to work. I enjoyed every – it*

*was great. That was a big wrench, I lost that and everything associated with it. Socially, people say exercise. I mean I used to do a lot – a lot of people say ‘Really?’ but there was a lot of walking involved.”*

For other participants, loss was centred around practical issues and finance.

P5

*P5: “Income wise I must have lost...”*

*Wife: “Well, you’ve lost a hell of a lot”*

*P5: “Fifty thousand a year. You know but that’s not due to the operations, that’s due to the illness, which I suppose you really can’t take into, you can’t be bothered to think about it, because you can’t it won’t happen, you won’t get that money back. You just draw a line and carry on and you’ve got to do that with everything.”*

P1’s quotes illustrate that he is still very much affected by the loss of his job and views it in a highly negative way. On the other hand P5 talks about moving on and not focusing on the loss. The difference in attitudes towards loss and the varying degrees of impact may be tied to the salience of loss in regards participant identity. It is clear that for P1 his job formed an integral part of his self-identity and QOL. He not only loved his job but it also gave a connection to family history as his father had also worked on the railway. Losing this not only meant losing his livelihood and causing potential financial issues, but also took away an essential part of himself. In comparison, P5’s loss of income does not seem to be tied to any core sense of self or identity. For him the sense of grieving was more practical, and therefore may be easier to cope with and move on from.

In trying to make sense of their cancer participants talked at length about their beliefs regarding the cause of their cancer. As many participants had been told their cancer had been present for a number of months or even years, participants tried to pinpoint when the cancer may have first started.

P9

*P9: “Of course they said, ‘Well, you’ve got a tumour.’ I never thought anymore about it at the time. That was it. Prior to that I really put it down to one night I was going to Peterborough in the truck, and I had to go into this haulage yard. It was locked up, except there was no padlock on, with great big metal iron gates. You know when the gate closes you put the peg into the ground?”*

*Interviewer: Yes.*

*P9: “Well, I had lifted it up and pushed this gate back, and of course it caught in the tarmac, and the gate come back with such a bang it caught me, and caught my eye and*

*whatnot...It didn't knock me out, but it put me down on the ground. I always put down that it was that what started it, the sudden shock. I don't know whether it can or not.*

P11

*P11: "Thinking back, he said, and I forget the size now, I'd probably had it for seven or eight years."*

*Interviewer: Oh, before that?*

*P11: Yes, in my body, growing. I had no real symptoms, but, thinking back, I remember... My daughter was married in Jamaica and we went out there. That was probably four weeks before. I was playing a lot of tennis and stuff, and eating a lot of spicy food. I had a few days of real discomfort. I put that down to either over-exertion or the spicy food, and, probably, it wasn't. It may have been something going on inside my bowel, but I just didn't know about it. A couple of times perhaps the year before, I was caught short, but I had no bleeding. I had no real pain to talk about. So, it came as a complete surprise to me that I had that. I was sent for a CT scan a few weeks later, and there was a shadow on my liver. So, I was referred to a consultant in Basingstoke, Mr X, who is a genius. Within a few months, I had an operation on my liver. I think, in July, I had the operation on my bowel, and in August or September, I had the operation on my liver.*

Not being able to fully explain or understand this lead to many participants feeling a lack of closure and being unable to put the experience in the past. This was particular evident with P11 who talked at length about wanting to know why this had happened and still not being satisfied with the answers:

P11

*"I saw the oncologist after that operation and asked her the question, "Why have I got it again? Is it the old one or the new one?" She also said she thought it was new. I'm still not sure about that, but it's irrelevant. It doesn't really matter."*

*"Having not got any answers to why I got cancer, because it could be hereditary... When I traced my birth mother, she told me her sister died of bowel cancer when she was 56, which was the age I was diagnosed. I told the oncologist, and I think she said, "There's a 10% chance it's hereditary. It could be a random neutrino come from a far... It could be anything." I'm a guy that wants answers, and there aren't. So, you put it just down to bad luck."*

*P11: "Now, I've got nothing to cling onto. So, it's just one of those things. It's the fickle finger of fate. I call it the 'random neutrino'".*

*Interviewer: The “random neutrino”? (Laughter).*

*P11: “Yes. It’s come from space. It just happened to hit one of my cells, “Ping,” and cause cancer. I’ve got no other explanation.”*

*Wife: “No, but, for me, I could say to myself, “I’m never going to know it. Forget it,” but he can’t forget that. He just keeps on: “I don’t know why I got it.” You’re never going to know, are you?”*

*P11: “It doesn’t concern me. It’s a rational view that if you don’t know why you got it, it’s just a random thing, and if it’s a random thing, it can happen... The fact that I got it twice and I was told that it was brand new: I’m not inclined to believe I’m unlucky enough to get two hits within the space of three years that are random. I suspect it’s the old cancer that stayed there because they couldn’t find it all. If that’s the case, well, what are the chances of there still being a tiny, little bit? It’s quite possible. That’s not a worry. It’s not like that. It’s just that I know that there’s a chance that it could come back. If it comes back, well, we deal with it at the time, and I trust that the NHS can look after me. That’s all okay, but I don’t believe I’ve beaten it. I just think I’m ahead on points. That’s fine, I think. That’s fine. I hope I die of something else, though.”*

P11’s relationship with his cancer and his long-term survivor journey appeared to centre around his efforts to try to understand his cancer, as many people would seek to understand an opponent or enemy. His inability to get a satisfactory explanation regarding the cause of this cancer meant he was unable to know what to do in the future to avoid this happening again. The fight was still not finished:

P11

*“So, I know I’m still in a fight. The fight hasn’t finished, and I’m ahead just on points. I have no idea how many rounds there are. I’ll only know at the end, and it won’t be me that knows. It will be whoever is left. Yes, it’s a lack of closure. Now, it doesn’t worry me. I don’t stay up at night thinking about it. It’s just a consciousness that that is a lack of closure.”*

Other participants shared this sense of frustration at a lack of explanation, and even displayed a lack of acceptance at the fairness of their illness and why they as individuals had got cancer. However, they then went on to say that they found this way of thinking unhelpful and tried not to dwell on it.

P2

*“There have been occasions where I could feel, “Oh, why me? Why this, that, and the other?” But there’s no point...Because nobody wants to listen to a moaner.”*

P3

*"It's hard to say isn't it because when you're um, well my father had prostate cancer and my mother had a stroke, um... and you sort of think well how will my life pan out with those kind of backgrounds but um... I don't know whether you go through life saying oh it will never happen to me, you can't really can you, um, it did happen so get on with it, you know I don't, just gotta be... you can't say why me"*

Other participants talked about how they tried to avoid thinking about it and the lack of focus on the experience. However despite this apparent lack of focus, the legacy of their cancer was such that when their health was threatened, even in a minor way, their first reaction was often that the cancer may have come back.

P10

*"Well, I think it was a very traumatic and difficult thing to have. I don't know what I mean by that, really. You just feel a bit... It's thinking about it all again, really. I don't think I'm just pushing it out of sight because I have no reason, in my daily life now, to worry about it."*

P12

*P12: "That's a hard one to answer, because I don't ever think about it. That's all the past now, as far as I'm concerned."*

*Interviewer: It's not something that you ever really think about?*

*P12: "No, I don't. Alright, say I get a mark somewhere or something, then I may see the doctor so I suppose at a time when something isn't quite right, you know. I think I had a spot on my tongue and I saw the doctor, just thinking in case it was, but that's about the only time. You know, something appears that shouldn't be there, then I might go and see a doctor. But no, I don't think about it at all."*

## **Living with cancer**

The theme of living with cancer focuses on how participants coped with and managed their cancer. Throughout the interviews it became clear that participants used a wide variety of strategies and coping mechanisms. The main strategies and support systems discussed by participants were social support, mind-set and mental attitude, religion and faith, and life focus.

## Social support

All the participants talked to some extent about the role of their social networks in their cancer journey. Many different types of social support appeared to be important and provide sources of emotional and practical support.

For many their family were viewed as very important and helpful sources of support right through from diagnosis until the present day.

P3

*"Well immediately afterwards of course it took quite a long time, a good few months to recover, obviously, because we'd retired here, and um, got family here and um I couldn't do very much for quite a long time, but of course I've got a very very supportive husband and family"*

P13

*"Yes, I'm a big family orientated person. I love family, I love being close. I love kisses, I love hugs. My family, I'm so thankful for them, for being around me, and for helping me through what I've been through. They've been very good, very supportive"*

However, in contrast, other participants expressed an attitude of not wanting to worry family or be a burden on them.

P12

*P12: "Yes, yes, a pretty big family but everybody gets on with their own lives, you know? I don't want them worrying about me"*

*Interviewer: No?*

*P12: "Well they do, but you know, they've got their own problems without worrying about me"*

*Interviewer: Why don't you want them worrying?*

*P12: "Well because they've got their own problems. You know, they know what I'm like, so they care for me and they keep an eye on me, but they know where I want to be"*

As well as family, friends and the wider community played an important role in many participants' lives. For P8 and P13, the church community had been particularly supportive both in a practical capacity, and an emotional one:

P8

*"We're even having a loo put in the church. We've got a good friend, who's the treasurer. She says 'It's ridiculous, you not being able to come to church. We'll have to do something about it'. She's very organised. So soon, the Bishop is going to come and licence a loo."*

P13

*"My church sisters, as we call each other. And yes, if they don't see me, if they can't come, they ring me, and they pray for me over the phone"*

For those participants in a relationship, their partner was a central source of support. Participants talked about the importance of these relationships and the importance of sharing their experiences with someone.

P11

*P11: "Every session I have with the consultants, my wife comes with me. Every one."*

*Wife: "That's his choice"*

*P11: "That's my choice, but I want her to hear everything. I don't want her to feel that I'm hiding anything, and also, it's a second opinion. Sometimes, especially when you're going through chemotherapy, you're not taking in. So she will listen. It's vital, absolutely vital that you're sharing it with somebody. Again if you don't have that it must be so much harder, I think. I don't know what people do if they haven't got a confidant."*

Many also described how they felt the experience was worse or more difficult for their partner, and the impact it had had on them. Primarily, this focused around a sense of helplessness and dealing with the possibility of losing them.

P11

*P11: "It's much, much worse for other people than for you. I think [wife's] gone through a harder time than I have"*

*Wife: "No, I don't think that at all"*

*P11: "That's what I think, because you've had to deal with it. You cope with it. You get through it"*

*Wife: "From our perspective, that's just worrying and how you feel going through it. Because we don't know and we're not going through it, it's harder watching, isn't it really? You wish that you could just take it off them for a bit. Do you know what I mean?"*

P6

*Wife: "Well, it was hard because I thought I was going to lose him"*

*P6: "Yes that was the worst thing for you, wasn't it?"*

*Wife: "That was the worst thing. I was thinking..."*

*P6: "I've always said it was worse for you than it was for me, really because..."*

*Wife: "We got rid of the bowel cancer, now it's gone to his liver. Then, just before Christmas, he started to bleed again. It had gone to bowel again. You think, then, 'This is it'. Then, when it went to the lymph nodes, I thought, 'Lymph nodes? This is really it'. So*



*that was the most horrendous time because I thought I was going to lose him. That was the worst, wasn't it?"*

For those participants who had strong social support and had found this an important aspect of coping with their cancer, this often made them reflect on what it would be like for those without this support.

P10

*"I think, if you haven't got anything like that, it can be even harder, really, and if you haven't got the support. There were people I met who were like that"*

P13

*"Yes, definitely. Because alright, I have family, I have my children and my grandchildren. I think about those who haven't. I have them, and yet, sometimes I feel depressed, I feel alone, and I have them. So imagine someone who doesn't have family, who had no children, no grandchildren"*

## **Mind-set and mental attitude**

On an individual and personal level, participants talked about the importance of having a positive mental attitude and approach to their cancer. Throughout the interviews, participants consistently talked about staying positive.

P2

*P2: "I always say, it's up here"*

*Interviewer: You're pointing to your head there*

*P2: "Think positive"*

P6

*"Well, I know because there are so many really sick people there. You've got to be positive, you've got to have a positive attitude because the ones that don't just die"*

When asked about his reaction to being told his chances of survival, P9 talked about the importance of believing he was going to be okay:

P9

*"There not being a chance? I didn't really. I'm not saying I didn't have time to think about it. I just kept positive all the time, thinking. 'I'm going to do it. I'm going to do it'"*

This was a view also shared by P7:

P7

*"I'm an optimist, I think. Well, I am. We'll always be alright"*

In addition to staying positive as a way of coping with the cancer, P10 talked about the link between mind and body and mental attitude and approach could influence the immune system:

P10

*"I think it's so important because it affects your ability to deal with anything, really, and it affects your immune system. So, it gets things firing that wouldn't be firing, instead of your immune system giving up. I think it's all connected, really."*

Having a positive mental attitude also translated in participants' actions and behaviours. Rather than focusing on the cancer, participants talked about the importance of carrying on with normal life and keeping active.

P6

*"Well it's tough to say, really. I don't worry too much. I don't dwell on it or anything. I just get on with it and accept it. That's what you've got, that's what you've got to get on with. So I don't really worry too much about it"*

Here, P9 talks about how doing up his caravan helped him to keep occupied and avoid focusing on the negative aspects of his cancer treatment:

P9

*"It did, because actually doing it all up, all the woodwork and everything, as I say, I was doing that while I was on the chemo, and the chemo never came into my mind. Because I had other things on my mind, cutting up wood and doing new frameworks here, there, and everywhere, that was it. I was doing that from eight o'clock in the morning until seven at night"*

For P7, it was his dancing, something he had been doing regularly before being diagnosed:

P7

*P7: "I would go dancing with a pump, pumping what's its. I used to go down on a Wednesday, have some treatment and have a pump fitted. Go back Friday and I would give them the pump back."*

*Interviewer: Did you make any changes when you were having the treatment to your life or anything like that?*

*P7: "No, I just carried on"*

An interesting question to consider in relation to the mind-set of the participants is whether these survivors discuss keeping positive as a result of hindsight and knowledge of their own survival, or whether positive and optimistic people are more likely to survive. Within the psychoneuroimmunology literature, the link between optimism, mood, and the immune system is well documented. Optimism and having expectations of positive outcomes in relation to health have been linked to more successful coping with health challenges, and better overall physical health (Carver et al., 1993; Stanton & Snider, 1993; Scheier et al., 1989). In addition, studies investigating the individual differences in responses to stress have found that optimism is associated with better immune response, such as increased helper T cells and higher natural killer cell cytotoxicity (Segerstrom, Taylor, Kemeny & Fahey, 1998). However, further studies exploring differences in acute and chronic stress have suggested that the positive effects of optimism only hold true for short-term or acute stressors, and can actually have a negative effect in the long-term (Segerstrom, 2004). For example, a study carried out with healthy women over a three-month period showed that when exposed to high-level persistent stress, the optimists showed more subsequent immune reductions than the pessimists (Cohen et al, 1999). An explanation for these temporal differences in immune response may be found in the biological interface between the immune system and cancer cells. Full activation of the immune system can result in the full eradication of mutant cancer cells, however long-term or chronic activation of immune cells in proximity to pre-malignant tissue may actually promote tumour development (de Visser, Eichten & Coussens, 2006). Therefore, if optimism is linked with greater immune function, optimists may be better equipped at dealing with short-term immune threat, but if cancer development comes to fruition and the immune threat becomes chronic, they may actually be at higher risk for tumour progression and recurrence.

Work exploring the effects of personality and disposition on the immune system is still unable to provide clear answers on the link between optimism and cancer development. Emotional suppression, helplessness, and fatalism have been found to be risk factors for the initiation and progression of cancer (Segerstrom, 2003), however denial and minimising the effects of cancer has been linked with more favourable outcomes (Garssen, 2004). In the current study those participants reporting positive mind-set and mental attitude also discuss implementing this through keeping going and being active. Therefore, if these activities act as minimising the effect of cancer, perhaps it is this that has contributed to their survival.

## Religion and faith

For those who were religious, a recurring theme was of being watched over and looked after. Participants found solace in the idea that something or someone was helping them.

P2

*"I have prayers said for me literally all round the world...Believe, or not believe, something was helping me"*

P10

*Interviewer: Do you think that you're being looked after and watched over?*

*P10: "Yes, I do. That's not to say that if you have a faith everything is going to be easy. It's not, and often it seems the opposite. People who have faith seem to have all sorts of problems but I think they own a different mind-set in the way they can deal with it then. I see other people in our church, through other things we do, who are remarkable, and they don't necessarily get an agreed result. I felt that throughout this, there was a higher power and I was being helped through it, whatever the future might be"*

P8

*"...knowing that I'm in God's hands. You pray about everything that's going to take place, and you commit things to him, and you just trust that it will be. There's a verse in the bible that we like, which says, "All things work together for good." That's been an underpinning for us when we meet difficulty."*

For one participant in particular, P13, being diagnosed with cancer had had a profound impact on her beliefs. Although raised in a Christian family she had not been a practising Christian for many years. Being diagnosed reignited her faith and become an incredibly important aspect of her coping and support system.

P13

*P13: "Oh God, I wouldn't like even my greatest enemy to go through that, because it's not nice. And you live from day to day. Because with me, sometimes I keep thinking 'will I be around for next week?'. But since I've been a Christian"*

*Interviewer: Oh, since then?*

*P13: "and joined the church, yes"*

*Interviewer: Oh, you weren't before?*

*P13: "I wasn't before, I read my bible a lot, and I trust and believe in God"*

*P13: "My mum has been a Christian for years, from the early '60s, and the week before I had the operation, she asked me, would I like her church sisters to say a prayer for me,*

*because I was going to have the operation? And I said, "Yes." So they came inside, and we had what you call a little prayer meeting. We sang and we read the bible, and they encouraged me to have faith in God, and that. And from there, I just started thinking. And I thought, 'Yes, I think I'm going to join the church.' Because to me, I felt that there was nothing more out in the world for me, actually."*

*Interviewer: How do you mean?*

*P13: "I felt as if joining the church, I felt safe. And when I read certain parts of the bible, I just trust in God, and in my mind, I felt that He would heal me. I had that faith that He would heal, because the bible says He's the healer. So I just had that faith that He would heal me, and He would see me through it all, which He did. I don't care what anybody says."*

Having faith and believing in a higher power also helped participants come to terms with the uncertainty of their treatment outcome and accepting the possibility of death.

P10

*"I've got a very strong Christian faith, and so I had a lot of support from that. I mean, I don't believe that this is all that there is. I can't honestly see that that could be true. So, I don't think of it as just you dropping into a void. There is obviously a sadness if you leave part of your family and all that, and I don't want to underestimate that, but I think it does give you something else; a positive thing."*

As well as providing strength and reassurance on an individual level, the wider religious and church community provided a source of social support.

P15

*"Yes, again going back to when I was first diagnosed, the local vicar came round and blessed us and what have we. He did what he would normally say because of the problem we had ahead of us, and we went to church whenever we could. Obviously, when we're out of the country we can't. We got great warmth from that and it helped us tremendously going to church and talking to people and praying."*

## **Life focus**

Life focus encompasses how participants chose to look at life, and how they framed their thoughts and experience. Among this theme, there was a contrast between those who had decided to live in the moment, and those who focused on the future. For some, these attitudes were short-term coping strategies used to cope with initial diagnosis, treatment, and recovery, however for others they had endured beyond this and had become long-term outlooks and approached towards life.

Participants talked about making the most of life whilst they still had the opportunity. Many described how they had gone on cruises or holidays.

P6

*Interviewer: Yes. It sounds like it was quite a difficult time and you didn't know how long you had and what the outcomes would be. How did you cope with that?*

*P6: "Well, it's strange..."*

*Wife: "We went on a cruise, didn't we?"*

*P6: "Yes. I never..."*

*Wife: "Never gave up."*

P9

*"As I say, I came out, I walked down on [town], and I cried my eyes out. [Partner] was with me at the time, and I said, "Sod it. We will go on a cruise." (Laughter) We went down and got the cruise. We got on the cruise. It was still in the back of my mind a bit, but I thought, "I'm not going to let that upset me on the cruise." Until you come back to reality again. You come back and then it hits you again; 'Oh, blimey.'"*

Another describes how they changed their attitudes towards money and spending:

P4

*Wife: "I think while you were ill, we did things like going to the Monaco Grand Prix. The insurance policy we had, which was due to pay the mortgage off, we bought a Jaguar instead." (Laughter).*

*P4: There was a little bit of living for the moment, which continues, actually.*

*Wife: "When he was so ill, there was a little bit of, 'Oh my goodness, let's just spend money because...'"*

In the longer term, some participants talked about not putting things off or worrying as much about the future.

P5

*"Things that were important aren't important. I think, now, I'm of the opinion that if I want something I go and get it. I don't think what's going to happen in six months' time. Well, I do six months' time, but I don't think about what's going to happen in ten years' time"*

In contrast to living in the moment, other participants found looking to the future helpful, especially in terms of seeing progress during recovery.

P10

*"I made a big chart of the times of it all, a timeline, so I could tick things off and so I could see progress."*

P9

*"I've not looked back really. I've not looked back. I always look forward all the time. So yes, that was it."*

Some talked about planning nice things to look forward to:

P15

*"Yes, we always had something ahead of us, like going away for a weekend, a simple weekend and what have we. Yes, there was always something there for us to do or people coming, possibly, who hadn't seen you for a long time and wanted to see you."*

Others felt a need to make sure everything was in place in case they had a negative outcome:

P10

*"I think the support I had was very reinforcing. I did think a lot about what might happen without me, but it's not as if I never thought about that. As you get older, obviously, you've got to make arrangements. We've made wills and everything. I've got three daughters, and I thought about how my wife might manage. One of the things that happens, obviously, if you've got a pension is that that is reduced a lot when the wife... My pension: it's halved, if you like. So, I did look at a few scenarios there to see."*

Participants used a wide range of strategies to deal with their cancer. Most of these strategies seem to be related to removing the focus on their cancer, and looking towards the future or to other areas of life. It is interesting to note that participants only talked about what worked well or what helped them, with little or no comment on what had gone badly or had made things worse. The reason for this is not clear, it may be that participant selectively remembered what had worked well and ignored the rest. An alternative explanation is that it could be a form of attribution bias. Attribution bias is a cognitive bias that refers the errors that individuals can make in finding reasons for their own behaviours and outcomes. When the outcome of a certain behaviour is positive, individuals tend to assume a greater amount of personal control and responsibility for the outcome, however if the outcome is negative, individuals are much more likely to assign this to more situational reasons outside of their control (Heider, 1958; Kelley, 1967). In terms of coping mechanisms, it is possible that participants only take responsibility for strategies that yielded a positive outcome as it only these strategies they believe to have been within their personal control.

## Aligning the long-term impacts: the person I've become

This theme encompasses the long-term changes that had endured as a result of participants' cancer. It explores how the cancer influenced participants' lives in the present day, on a personal level, in their interactions with others, and in relation to the long-term practical implications.

On a personal level, participants described how they had changed both emotionally and physically, and how their relationship with themselves and their self-concept had been impacted. On a wider level, participants talked about their relationships and interactions with others, the changes in their perceptions of others, and in their views on life.

### Emotional impact

Talking about the emotional impact of their cancer was one of the few times participants focused on the negative aspects of their cancer journey. For many, there were a wide range of enduring negative emotional impacts. Some participants described how a side effect of their chemotherapy treatment had been a sense of paranoia and fear, which although faded, could reoccur from time to time in the present.

P1

*"That troubled me for a long time. I still don't really like to look at it now but it doesn't affect me as much as it did then. I had a few things, it's difficult to explain. One was, the big junction up here, the road, maybe it was there but every morning in bed, early hours of the morning, late at night, I could hear a motorbike come down there and stop. In my mind they're coming for me"*

*"Another thing which was more difficult to explain was if I got up to use the bathroom in the early hours of the morning, late at night, when I came back to go to bed in the bedroom, I knew they'd been. If anybody said, 'who?' I don't know. 'What did they do?', I don't know, but something in my mind..."*

Feeling sad and upset was an enduring emotion for many participants.

P1

*"Yes, that's another thing I was coming to. I thought that Jon Denver song, Some Days are Diamonds (Some Days are Stone), is totally true. It can wash over me. I just break down and cry. Somebody said, 'What's the matter?', I cannot say"*



Even P3 who had been overwhelming positive throughout her interview, talked about feeling low:

P3

*"Well you do feel low don't you when you've had a huge event in your life like that, but er as I say I'm fairly pragmatic and just think it's happened so just get on with it"*

In a reflection of the earlier theme of lack of closure and the cause of their cancer, participants expressed worry and feelings of uncertainty about their health and whether the cancer was going to come back. Many talked about experiencing fear whenever they felt unwell.

P5

*"I don't want to be obsessed with health, but when you go through that, you are obsessed with health, you worry about stubbing your toe, you worry about getting a cold, you worry about getting too hot. If you get too hot two days in succession, you don't put it down to the weather, you put it down to 'something's going wrong'"*

*"I think you'll always worry that once you've had cancer it's not the end of it. If you have tonsillitis, they take them out and that's the end of it...You're not going to get tonsillitis again"*

Throughout all the interviews, what became clear is that there was no single affect related to cancer. Participants experienced many different feelings about it, often within the same thought or reflection. This can be seen more clearly in the following quotes from P1 as he talks about the conflicting emotions he experiences when reflecting on the long-term impact of his cancer:

P1

*"Well you've got to be grateful. It would have been a darn sight worse. It took a lot of thing from me. I lost all my confidence. As I say, I lost my job which is a great big thing to me and everything involved with that so I was disappointed, is that right, upset about that."*

*"I always says to myself, but then again because I say, 'well you've got to be grateful', but I do say to myself, 'I shall never be the person I was before'"*

In these quotes, it seems that P1 experiences feelings of guilt and believes he is being ungrateful. He expressed anger and resentment at the cancer for taking things away from him, but at the same time he reflects that he has survived when many have not, leading him to be conflicted in his feelings towards his experiences and current life.

In addition to experiencing enduring negative emotions, participants also talked about changes in their emotional-self and mental approach to life. Both P4 and P5 talked about having less patience as a result of their cancer:

P4

*“Since the experience, my temper has been shorter. I was never a tolerant person, and I’m even less tolerant now”*

P5

*“Like I say, I’m definitely on a shorter fuse and, really, people do wind me up, a bit”*

P13 described how she had become more emotional as a result of her experiences:

P13

*“Emotional problems, sometimes I get very emotional about...Sometimes I just sit here and I just start crying. And then I think ‘What am I crying for?’, but it just comes over me, I just get emotional”*

*“No, that’s since I had the cancer, I get very emotional. I find I get this sometimes”*

## Physical impact

One of the most significant long-term impacts on participants was the change to their physical self and their bodily functions. In adjusting to the long-term impacts of their cancer, participants had had to adjust to living in a body that still showed signs of having experienced the disease. For some the changes were purely aesthetic, however for others these signs presented as long-term functional changes to their bodily experiences and functions.

One participant talked about how as his liver had regrown, he had been left with a large bulge in his abdomen, which affected his yoga practice:

P7

*“The only thing is, I got this [bulge], and when she says ‘Lie on your stomach, we’re going to do the Cobra’, I think ‘Oh God’, I’ve got to wriggle my way around because I’ve got to get comfortable. Well, I’ve got a bit sticking out here, which is not there in the morning until I get up, the hernia. I’ve got a bit sticking up, which probably should have been sewn in a bit better”*

For others, the chemotherapy treatment had taken away the feeling in their hands and feet.

P11

*"Yes, as a side effect of the oxaliplatin. I've lost sense of feeling in my fingertips... it's probably about 30% feeling. That's never come back"*

P6

*"Yes, I had so much chemo that it deadened the nerves in the end of my fingers. They said in oncology that if it didn't come back within a year you've got it for the rest of your life, which I have, because there's no feeling in the tips of my fingers. Which is a bit awkward at times, I do drop things occasionally, smash cups"*

*"The bottom of my feet as well, I've got patches on the bottom of my feet which are the same. It's damaged the nerves, that's what it's done. Some parts you can feel, some parts you don't"*

Participants also experienced tiredness and fatigue or had trouble sleeping.

P3

*"Fatigue, I mean obviously you're terribly tired, I get tired very easily anyway, I mean I always have done, but I do get tired very easily"*

P2

*"I've never been a good sleeper. The last two nights I've not slept too badly, but the night before I reckon I had about four hours sleep. That was it. I listen to the radio and I listen to CDs"*

As may be expected given the nature of participant's primary colorectal cancer, the biggest physical impact had been on their bowel function and ability to control their bowels. The majority of participants had never regained full control over their bowel, and still had problems with soiling and urgency. This created significant restrictions in terms of what activities participants felt comfortable doing. For most, their lives were constrained by their proximity to a toilet and the fear of what would happen if they had an accident.

P5

*P5: "The only place we can walk around is, really, shops"*

*Wife: "and sea fronts"*

*P5: "yes, and places where you know there are going to be loos. I'm governed by what I can do. We're going out this evening so I can't really go out this afternoon and stay out until this evening. If we're going out this evening, I have to make sure I go to the loo"*

*before we go out and then I can go out, but I can't stay out for... I suppose I'm limited to about four hours at the most, aren't I? Because I've got irritable bowel, because of...[the cancer]"*

P8

*"Having that trouble with my motions, and having to be careful about where I went, I know every loo there is in [town], and that kind of thing. Going to church was difficult because a lot of the churches around here have got no means of helping you. So I couldn't go to church quite a lot when I wanted to"*

P13 described how she always had to plan her visits into town to get her shopping, and the feeling of embarrassment when she had an accident:

P13

*P13: "Very planned. Because of my stomach, again, I have problems, like what I was saying here"*

*Interviewer: What? Going to the toilet?*

*P13: "Going to the loo. It comes down on me, and I'm not realising. And that's very embarrassing. I've been in town already, and I just park the car, and I have to turn back, go back in the car, and drive home. Because for me, I thought I'd rather do it in the car. You get what I mean?"*

*Interviewer: Yes*

*P13: "I'd rather it came down on me in the car, than me walking to go, in the [shopping centre], to the loo. Because it would come down, then, on me. And that's what I have difficulty with."*

For those who had a colostomy bag, either temporarily or as a permanent consequence of their operation, problems with the bowel were even more pronounced and complex.

P8

*"That was very messy. Also dealing with it was difficult, too. After a year, it had got a lot better. I saw Mr X again, and we agreed that they'd do everything to remove the bag and go back to treatment. At that time, I was on loperamide. So that's what happened; they removed the bag, and sewed me up again. We had quite a lot of trouble in the early disease, because I had very little control over my bowels. For a long time, I had the feeling that my whole life was being dominated by my gut. I had, sometimes, 30 movements a day."*

P6

*"It seems to play up then. It's almost like - I don't whether it's the extra food all in one go but it only happens at night. It doesn't happen - we always eat at lunchtime; our main meal. It's almost as if you get a spasm where everything turns - it's almost like diarrhoea then. You get so much in the bag that it's pushing the bag away from you; it's too much in the bag."*

*Wife: "We had a disaster the other week. You're brother-in-law's 80th birthday party."*

*P6: "Yes, it happened there."*

*Wife: "I could tell he was having problems. Of course, these places don't have a disabled toilet, which you need..."*

*P6: "Yes, it's very difficult."*

*Wife: "...a proper disabled toilet."*

*Interviewer: Well, you need some space, don't you?*

*P6: "Yes."*

*Wife: "Yes, and to clean it all out because once the bag - it pushes the bag off then it goes all over everywhere. So you need somewhere, don't you?"*

*P6: "Yes."*

*Wife: "Of course, when you're out like that there's nowhere."*

*P6: "There isn't anywhere, no. It's very awkward, that."*

Having accidents as a result of the bag bursting was something all participants with a stoma bag talked about. Here, the wives of P8 and P4 talk about this:

P4

*Wife: "The thing I hated – the worst bit was when he had that colostomy bag, and when we had accidents, having to take him in the shower and hose him down like a two year old, but you have to laugh and get over it, really, don't you?"*

P8

*Wife: "Sometimes the bag would burst, even when I was trying to do it. He became very, very sore. It was a terrible mess then. It was very, very painful."*

Even participants who had not had a colostomy bag talked about their worries of how this would have affected them and the difficulty of dealing with this.

P11

*P11: "Probably the worst thing: when I was in the hospital being prepared, they marked me up for a... Is it a 'stoma', the bag?"*

*Interviewer: Yes, the bag.*

*P11: "They marked me up for that. I saw the surgeon just before the operation and said, 'If that's necessary, I don't want to wake up.'"*

*Interviewer: Really?*

*P11: "Yes, and I don't know why I said that. It was perhaps just that that would be a real signal of my infirmity; whereas, I feel I can fight this, and I really do feel as if it's a battle between me and the cancer. That's a strange thought because it's nonsense, probably, becomes a personal battle. If I had to wear a bag all the time and live with the consequences of all that and the paraphernalia, that was something I didn't want to... Now, that probably isn't true. It was just something I said at the time."*

*P12*

*P12: "So I said to my sister, 'They haven't done it. They haven't operated' when I came to, because she was there. I said, 'They haven't, because there's no bag. Where's the bag?' Anyway, I didn't have to have one, so..."*

*Interviewer: Yes. Were you nervous about maybe having a bag?*

*P12: "I was more nervous about that, I think. You know, because you've got to take a different lifestyle then, haven't you? But I haven't, I've kept on doing what I've always done."*

*P13*

*"And also, when I had the bowel, they were measuring me up for a bag. That really scared me. I thought, 'Oh, no.' That really scared me, but I didn't need it. That was the first thing I heard my son say when I came around; 'Mum, mum, you didn't need the bag.' Because he knew. He was crying about that... I really was, I was overjoyed. Because the consultants, they said I might. Because they said I might need it, but in three months' time, and then they would take it away. But just hearing the bag, that really scared me. Yes, but thank God, I didn't have to have it."*

For those with bowel problems, both with and without a colostomy bag, one of the biggest challenges was travel. This ranged for every day excursions, to holidays and long-haul flights.

*P4*

*Wife: "I think travelling was very, very difficult, because there were no facilities at all. Once we were travelling in an airport, and he had to – he was in a bit of a state. He could feel himself, he had to go and change, but there was nowhere. So you went into the baby changing area. Of course, it took him ages, by the time he'd cleaned out the mess and everything, and when he came out, there was a whole queue of mothers being abusive to*

him. But I thought, 'You do not realise what he's had...' And you can't go into a man's toilet to do it. There's nothing."

P8

P8: "Things I can remember, when our son and family came over from Australia, they had transport and they wanted to go and see things. That proved a real problem, because we had to look for pubs where I could use the toilet. It was quite a frightening thing, setting off, going somewhere, and not knowing where you were going to find a loo that was open."

Interviewer: Did it make you feel quite anxious?

P8: "Yes, and embarrassed, because three grandchildren in the car, and they're all laughing at granddad having to find a loo, and that sort of thing. Not that them laughing at me, I minded, but it was just something to cope with."

Being abroad with a colostomy bag and the practical issues surround this was also a cause for concern. Here, P6 and his wife talk about challenges with insurance and the worry about something going wrong whilst being abroad:

P6

Wife: We do think like that, actually. We'd had such a lovely one last year - our friends want us to go to the USA and I'm 'Uhhmm.' The trouble is getting the insurance for him; they don't want to know.

P6: "No, they don't".

Wife: "They won't cover you for colostomy, won't..."

Interviewer: Really?

P6: "Yes."

Wife: "Yes, they won't cover. However many years ago and how long, it won't cover you for colostomy in case something goes wrong and you've got to go in and run up a huge bill. That is the only problem with going to America. We're all right - because our youngest son lives in Thailand. We've been over there. I said, 'They won't cover dad for his cost.' He said, 'It doesn't matter, mum, you can go into private hospitals here and they'll do it.'"

Many participants talked about the different strategies they had for managing their bowel problems. The most common were controlling it through medication, and having an emergency pack of clothing or supplies with them in case they had an accident.

P5

"Well, it's like now, you know, we can't really go away anywhere. What I've done before, when we've gone long-haul, I've just dosed myself up with Imodium so I'm constipated

*and cope with it that way, but I don't want to do that day in, day out. We couldn't do an escorted trip or anything like that, where you get into a coach and you get driven."*

P8

*P8: "I've got a bag that I take with me all the time. It's got underpants, and it's got a pad, and it's got various other things that I need."*

*Interviewer: Very organised.*

*P8: "Yes. That's just a way of life, really. Most of our friends in the village know that I disappear to the loo. If I'm in the sitting room and I get up, they know where I'm going. It's all just accepted."*

For some, wearing pads had become a normal part of life.

P2

*"I don't wear the big pads. I do tend to wear panty liners these days"*

P8

*Wife: "One of the greatest difficulties, I think, has been that he's had to be padded up for the last 12 years for 24 hours a day. That's a difficult thing."*

*Interviewer: Mmm, how do you mean? What? Have pads on?*

*Wife: "Always, yes."*

*Interviewer: Yes.*

*P8: "From the very early stages, the nurses said, 'Soon, you'll be able to do without a pad,' but I've never been - like today, I couldn't have done without a pad."*

## **Intrapersonal and interpersonal changes**

On a wider level, going through cancer treatment and surviving had for some been a catalyst for becoming more empathetic and understanding of others. Participants talked about how they felt more connected with people and felt they were kinder and more sympathetic.

P4

*"I don't I do anything in my life that is different because of the experience. I think, as we've already explained, clearly one has a different view and a different sympathy of what's going on with some people, and that kind of thing..."*



As well as the experience her cancer, P13's new religious beliefs added to her feelings of being more sympathetic of others:

P13

*P13: "Yes, it makes me more considerate. I'm more sympathetic. Not that I wasn't sympathetic, but I find I'm more sympathetic now, for what I've been through. And I'm more understanding to what other people are going through. I'm very understanding, because I tell you, if I wasn't...And what made me so understanding is being in the church. When I think, many times, when I'm driving and you have, out there, the Somalians, and they can't drive, and they're out on the roads. Before I got saved, I would curse terribly"*

*Interviewer: Really?*

*P13: "I would. But now, I don't. I'm more understanding, even though I know what they're doing is wrong. X Road is a busy road, and they're doing three point turns on X Road. Now, tell me...The bus has to stop, everything has to stop. You don't do three point turns in the middle of a busy road. So I find I'm more understanding. I'm more patient too."*

Here P10 talked about viewing people more holistically and valuing different aspects of people:

P10

*"I think I'm perhaps a little bit more... I don't know whether it's compassionate, but something like that, than I was, and a bit more understanding. I worked for a company where they wanted only the best people and all that. You were looking at certain characteristics of human behaviour, but that's only a part and not necessarily the most important thing. Perhaps I see the value in people who have gone through difficult situations, whatever their background, and cope with things. I can relate to them much better."*

P8 talked about how he felt that being a cancer survivor had fundamentally changed him as a person. He described how being a cancer survivor gave him a unique insight into life that could only be gained from going through this experience:

P8

*"Yes I was just trying to put my finger on – difficult to put into words. It's the relationship with other people. That feeling I'm not a recovering cancer victim, I'm just a person. There is a sense that, because of what's been done to you, you have to relate in a different way to the things around you. It does put you in a different class, I think, from other people who have never suffered of an illness. In a sense, you are grateful that you're still alive. You've got so much to be thankful for. How that relates to your meetings with other people, it puts you slightly differently. It's like somebody who's had a death experience, they talk about that. Not that I feel that..."*

In contrast, due the serious nature of their cancer experience and their experiences of treatment and recovery, other participants described how they were less patient with people and had lower tolerance levels.

P5

*“To be quite honest, people. People that whinge and moan. I know we’ve been moaning for the last hour, but people who whinge and moan about ‘I’ve got this wrong with me’, it’s that type of thing. Like the lads next door, you know, they have time off work for one day ‘flu. I mean, ‘flu doesn’t last a day. Everybody knows that, but they still think they’ve got ‘flu, they haven’t got a cold, because they never actually really had ‘flu. I’ve got no patience with that type of thing. I shout at the television more don’t I?”*

It is possible that for P5, because he had experience a severe and life threatening illness, his benchmark for what constitutes a health problem deserving of sympathy was now much higher. Many individuals perceive the world, and interpret others’ experience within the world, from the perspective of their own experience (Goffman, 1974; Mead, 1934). They understand others through their experience of themselves. For someone how has suffered a very serious illness, it is possible that this would shift their baseline of illness experience, and what they perceive as acceptable illness behaviour. In P5s case, he had tried to carry on as normal throughout his cancer treatment. It now seems inconceivable to him that someone would find it acceptable to take time off for something as minor as a cold.

For many participants describing an increase in empathy and understanding, this led to a feeling of wanting to give back to the community and wider society. Participants talked about wanting to help others. This ranged from their motivation for taking part in the interview, to an increase in charity work.

P1

*“When you wrote to say about this I thought, ‘If it helps somebody just a shade, then that’s got to be good’. I wanted to give something back if you like. I thought, ‘If that helps”*

Here P15 talks about how she and her husband now support a number of charities, including those for cancer patients:

P15

*“Yes we do, and Dr X with [Charity], we do a lot there and cancer. We have a number of charities that we help and we’re patrons for [Charity].”*

As discussed in the earlier theme of 'Living with cancer' participants' partners and spouses played a key role in coping with their cancer and providing support. In coming to terms with their life after cancer and the long-term impacts, many participants described how their romantic relationships had been affected.

Many describe how they had become closer as a result of their shared experience. On one side having the support of their partner throughout a difficult and emotionally challenging period in their lives, and on the other side seeing their partner go through a potentially life-threatening illness.

P11

*P11: "I think it probably brought us closer together. Not that we were distant at all, but just that closeness..."*

*Wife: "Yes, there is a difference now, I think"*

*P11: "I think that happened, and I'm more dependent on her than I was, which I don't mind at all. Actually, that's wonderful"*

*Wife: "He's saying that because you're here" [laughter]*

*P11: "No, I mean that. I don't think it's affected it other than that. We spend a lot of time together. We enjoy our company. We can go on holiday without the kids these days, which is wonderful"*

For some participants, particularly the male participants, their cancer treatment had had a long-lasting effect on their sexual function.

P5

*P5: "Well, everything shrinks and if you don't use it..."*

*Wife: "No, but also the nerves and everything have gone, haven't they?"*

*P5: "Yes"*

*Wife: "The surgery finished all that"*

P6

*P6: "Yes, the chemo kills everything off I'm afraid... then radiotherapy together, that was the end of a sex life, really."*

*Wife: "Yes unfortunately"*

*P5: "I can't do much about it I'm afraid...I'm very lucky that she understands"*

*Wife: "No, it doesn't matter"*

*P5: "You can't do much about that, I'm afraid. Some people, probably, wouldn't like that but we just get on with it"*

*Wife: "Yes that is one thing we lost but he's here"*

*P5: "Yes, that's it. That's what counts, isn't it"*

For some this had meant a change in the type of intimacy shared as a couple. Some talked about an increased appreciation for each other and a different type of tenderness. However for others, these changes had not been worked through in the same way, and had caused a gap to appear between them.

P8

*Wife: "Can I be very frank?"*

*Interviewer: mmm*

*Wife: "When you have these operations, your libido goes completely"*

*P8: "Mmm hmm"*

*Wife: "It went completely, your interest"*

*Interviewer: Well, it is a question I have, actually, so yes*

*Wife: "Yes. I thought I'd be frank, because he would never mention it"*

*Interviewer: "So I imagine that's quite a big change for both of you"*

*Wife: "Yes"*

*Interviewer: How did you cope with that?*

*Wife: "I found it hard for the first year or so, but then I adapted and adopted. Yes."*

*Interviewer: Has it changed the dynamics at all, for your relationship?*

*Wife: "Yes, because I don't get as many hugs either anymore. It all goes together. So that does. We're very fond of each other, etc...but this illness has definitely caused a break in any kind of physical – whatsoever. It's very unusual for you to embrace me, isn't it?"*

*P8: "Yes. That's my Scottishness"*

*Wife: "Partly, but partly the illness, because you've always been Scottish"*

For others, surviving their cancer treatment had given them the opportunity to start a new relationship. P14 talked about how her relationship with a new partner and how their sex life was better than it had ever been before:

P14

*P14: "I have a new man in my life. I've known him for over 50 years, he was married to my cousin, and he was at school with my husband...In actual fact, we've got together. To be honest, the sex is fantastic"*

*Interviewer: Is it? That's great.*

*P14: "Yes, yes"*

*Interviewer: You haven't had any problems with the bowel? It hasn't had any effects?*

*P14: "No...In fact, if anything, it's better...It's funny, he says it's the same for him. Now, our age group, sex was so different then. I think were so pressurised. There wasn't a contraceptive about that there is now, so you didn't really indulge in sex before you got*

*married, because you were dead scared of getting pregnant. If you did, you were sent away, or whatever. So there was always that fear. When I got married, I don't know how we managed it, but I didn't have a child for nearly two years. So that was okay, but that was an accident, it wasn't planned. X, my partner now, he said he hadn't had sex with anybody before he got married neither had my cousin, and they were sort of, as it were, fumbling in the dark, and I don't think anybody experimented then like they would now.*

*Interviewer: I think there have been quite a lot of changes, yes.*

*P14: "In fact, because I've now got an iPad (laughter) I went on one of these sites. I have opened his eyes to a lot of things. He said, 'Good grief, I never knew, have you always been like this?' I said, 'No, only since I met you'"*

For others, the experience had caused them to reflect on the lack of a romantic relationship in their lives, and what difference this would have made. P12 in particular talked about how his social life and behaviour would be very different if he had a partner. Here he talks about his drinking habits and how his social life centred around meeting friends in the pub:

P12

*"Well I cut down a bit. Well, I drink over the units anyway so...God, I couldn't have survived on two pints a night, could I? Not at weekends. But say I had a partner, I think life would be a little bit different...because my social is outside. But I mean, if you've got a partner it's a bit different. So I suppose that's a little bit of why I'm like I am. You know, you can't say it wouldn't be any different, it would be, but I think that's why I am like I am"*

P13 also reflected on not having a romantic partner in her life. She describes her conflicting views on what she would want. She talks about missing the companionship and emotional intimacy of this type of relationship, but not wanting the physical intimacy or domestic aspects.

P13

*"So I'm on my own. As I say, sometimes I feel lonely. Just somebody to talk to, not sex. Because right now, I couldn't go through that. My daughter, I talked to her, I said 'Where sex is concerned, I've had enough. But companionship.' Because I couldn't go through that now, the washing, the cooking, the ironing. I hardly cook myself. Washing, yes, just my bed clothes and my few little bits and pieces. And I get someone in to do my ironing for me. That's enough. If I had a relationship, I'd have to be planning, and I'd have to be worrying about what to cook..."*

On an intrapersonal level, participants talked about the impact their cancer had had on their sense of self and identity. Participants talked about feeling more fragile and vulnerable as a result of their experiences.

P5

*"To a certain extent, because when I had the first operation, I felt really vulnerable, whereas I've never felt like that before. People knocking you in the street, and things like that. I felt very insecure and weak"*

P11

*"More fragile. I would not have considered myself fragile before, but I'm more fragile now, and I wonder what it will be like in 10 years"*

Others felt that the experience had fundamentally changed them as a person and in all aspects of their life.

P1

*"I always say to myself, but then again because I say 'You've got to be grateful' but I do say to myself 'I shall never be the person I was before'"*

*"Oh yes, it changed me I think in all aspects, as I said earlier, more mentally which can be sometimes worse perhaps, I don't know, but more mentally than physical. Yes, everything in my life has changed really"*

Although the predominant message from participants reflects definite intrapersonal changes, there were some who felt that the cancer had had very little impact on them or their identity.

P7

*Interviewer: Do you view yourself differently since having the cancer?*

*P7: "No. No."*

*Interviewer: No. Why do you think you haven't?*

*P7: "Well, as I say, it's like having a cold as far as I'm concerned"*

P12

*P12: "No no, I don't, honestly. I mean it was a cut here, a cut there, and that was it. It was sort of 12 months that you had to behave and not do what you used to do. I mean, Dr X, or Professor X, whatever her name is, I don't expect she'd want to hear what I'm saying but...(laughter)"*

*Interviewer: And why do you say that?*

*P12: "Well you don't operate on somebody and they carry on with their normal life"*

These thoughts from P12 resonate with earlier discussions about what a cancer patient should be like. Participants held preconceptions about what having cancer would be like, gathered from

many sources such as TV shows, films, or personal experience within their social circle. The fact that participants did not take responsibility for their survival and put this primarily down to luck, meant that in many ways they questioned whether they were normal or if their experiences were acceptable.

## **What is the relevance of the EORTC questionnaires to this population?**

The final aim of this work was to explore the relevance of the EORTC QLQ-C30 and LMC21 questionnaire domains to this population. Accordingly, the last section of the interview schedule asked participants to look at the EORTC questionnaires and to comment on whether they felt they captured their experiences as long-term cancer survivors. The focus of the EORTC questionnaires is primarily on symptoms related to the cancer and to the treatment of cancer, and the use of this to extrapolate HRQL; whereas the focus of participants was on their wider experiences of cancer, of their relationship with cancer and with themselves, how they adjusted to and coping with their cancer, and the long-term changes that had endured. From the results it is clear that the EORTC questionnaires do not hold significant relevance to this population or give a full picture of their QOL.

P6

*“Most of them, really, don’t affect me anymore, Fatigue, nausea, no problem with that, pain, no, shortness of breath, no, sleeping, I don’t have any problems sleeping”*

P9

*“A lot of these I could turn around and say ‘Most of them don’t apply to me’...it was really all in the short-term. In the long-term I don’t really think it applies. I really don’t think it applies anymore”*

P12 described how he felt that whilst these questions may have been relevant in the short-term, they did not feel appropriate as a long-term survivor:

P12

*“I don’t know. I mean, should a lot of those questions be asked, say, two or three years after I had the ops, or what?...Nine years, or ten years down the road, what do you ask somebody if he’s alright?”*

P15 also talked about the timing of the questionnaires and also went to suggest that perhaps it might be relevant for other people rather than herself:

P15

*“A lot of those things were there in the first year, aren’t they, unless people are suffering with tummy problems still, pains still? I don’t know. I suppose you could do, because I’ve got nothing to report, have I? But then that’s just me”*

The results of this study and the themes that have been identified bear little relation to the content of the questionnaires. This difference in content may be due to several reasons. Firstly, the EORTC questionnaires were designed to measure short-term QOL with a focus on the immediate effects of treatment and recovery. As long-term survivors these issues cease to become patients’ main focus, and instead other issues become more important. Secondly, the aim and method of data collection is vastly different. As the method of this enquiry was open-ended qualitative interviews, patients were given free rein to talk about QOL however they felt it applied to them and to discuss issues they themselves felt were important. On the other hand, the EORTC questionnaire only gave patients the chance to answer pre-set quantitative questions, with no room to offer further explanation or add any additional information or areas of QOL that they may have felt were missing. It may be that some of the areas discussed in these interviews were important in the short-term as well, but were not reported as the measures did not allow for this. From the results it is clear that the EORTC questionnaire designed to measure short-term QOL is no longer relevant for this patient group and, additionally, that qualitative enquiry may offer greater insight into the subjective patient experiences versus a set quantitative questionnaire measure.

Overall the themes of this study have offered an insight into the long-term cancer journey. Firstly by exploring how participants understood cancer and their ‘cancer-self’, their coping strategies for dealing with the impact of cancer, and finally the long-term changes that had occurred as a result of their experiences. In coming to terms with their cancer, patients go through many adjustments regarding their ‘cancer self’ and their views of cancer. Much like examining oneself in a mirror, participants reflected on who they thought they should be and how they should be feeling or behaviour, versus the reality of experience. Many talked about not fitting the stereotypical mould of ‘a cancer patient’ and how they felt fraudulent in accepting sympathy or celebrating survival. Due to the complexity of experience many turned to the cancer community for shared understanding and experiences. For most, being diagnosed with cancer was the first time they had experienced their own mortality and the possibility of death. Through facing mortality and surviving, some participants described how their priorities in life had changed. Focus on family, friends, enjoying life, and being grateful were often discussed.



Despite the fact that the majority of participants were nearly 10 years post-surgery and that some had even been discharged, they still described feeling worried about recurrence and being more vigilant of their own health. Whereas pre-cancer any slight pain or discomfort may have been dismissed, now the initial thoughts were of the cancer coming back. An explanation for this may be found in participants' discussion around acceptance and closure. For some, the lack of explanation regarding the cause of their cancer meant that they were unable to find closure. By not knowing what had initiated their cancer in the first place, they articulated some helplessness in avoiding this in the future.

In living as a long-term cancer survivor, participants had developed a range of coping strategies. The most common focused on having a positive mind-set and mental attitude, and as a result of this keeping active and keeping going with normal day to day life. Participants talked about believing they would survive, that they would come through the darkness of treatment and recovery and continue with their lives. The importance of family, partners and wider social support was also clear. Having emotional and practical support from a range of sources helped participants to deal with their cancer, and their experiences as a cancer patient. For some, the Church community and their own religious beliefs were particularly salient. In an echo of conversations about positive thinking, participants' religious beliefs and faith acted as a light at the end of the tunnel. The comfort in knowing they were being watched over and looked after acting as an importance source of solace.

In moving on from discussions around their 'cancer self', participants talked about the long-term impacts of having cancer and their new 'post-cancer self'. These thoughts moved away from the primary experiences of cancer, to what the cancer had left behind. Enduring emotional and physical changes were evident in all participants. Those participants who talked about their emotional experiences described feeling more sensitive, fragile, and prone to increase emotional outbursts. Others described increased feelings of empathy and understanding for others. Having experienced a significant health trauma themselves, they were now more able to relate to others and felt a greater need to care for their community. On the other hand others described feeling less tolerant of other people and having a shorter temper. All participants articulated feeling grateful and lucky to be alive. In surviving such a traumatic experience, the appreciation of life was clear in nearly all participants. Although sometimes tinged with feelings of guilt, the expression of feeling lucky was an on-going thread through the interviews.

In terms of physical impacts, the long-term implications of the location of their cancer were clear to see. On-going bowel problems affected nearly all participants, both with and without colostomy bags. Not only did this mean dealing with the practicalities of these problems on a

personal level, it also involved restrictions and limitations to their day-to-day lives. Travel, being out and about, the locations of and access to toilets were all described as being new challenges resulting from the cancer. In addition to bowel function, the sexual function of some participants had been irrevocably changed. This not only caused changes to participants' sex lives and physical intimacy, but also impacted upon their relationships with the partners on an emotional level. The degree and type of change varied across participants. For some it was seen as a loss that has not been addressed or adapted to, for others it meant a change in the type of intimacy available and a shift in relationship dynamics.

These results will now be discussed in relation to the study aims, the implications for clinical practice, and future research.

# Discussion

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The aim of this study was to investigate the impact of CRC with liver metastases on long-term QOL and survivorship experiences, using a qualitative approach. Overall 15 participants were interviewed, 5 women and 10 men. From these interviews 3 main themes were identified; 1. Cancer and me: establishing a relationship with cancer, 2. Living with cancer, and 3. Aligning the long-term impacts: the person I've become. The results will now be discussed in relation to the research aims.

## **Aim 1: To explore the impact of CRC on long-term quality of life in cancer survivors at least 5 years post-surgery**

The results show that experiencing CRC with liver metastases can have profound impact on individuals, both physically and emotionally. Two of the most prominent physical changes reported by participants were firstly bowel and stoma issues and secondly changes to sexual function and sex life. Nearly all participants reported on-going bowel issues, regardless of whether they had a colostomy bag. Participants discussed having problems with diarrhoea and lack of early warning signals for when they needed the toilet. For those with a bag, they described incidents of their bag bursting, or difficulties in finding suitable locations to change and clean their bag. This had led to embarrassing and distressing situations where they had experienced accidents in public or in their own cars due to not being able to get to the toilet in time. Not only had this caused them significant emotional distress, but it also caused many practical restrictions in their day-to-day life. When planning to go on day trips or to go shopping, participants described the need to identify where all the accessible toilets were in case of urgent need. Many said they were restricted in the types of locations they could go to; where previously they had enjoyed long walks in the countryside, now they went to seafronts and other places with public toilets. Travel was also a particular concern discussed by participants, including the lack of facilities for changing colostomy bags, or the worry about taking a long haul flight with limited toilet access. Some participants described the fear of going on car journeys where the route was unknown, and feeling anxious and embarrassed by the situation. Others talked about using strategies to cope with travel, such as taking medication to cause constipation or wearing pads.

In addition to on-going bowel issues, decreased or limited sexual function were one of the main physical changes experienced by participants. This was particularly pertinent for males. Undergoing surgery and chemotherapy had had a significant and long-lasting effect on their

sexual function and sexual desires, and for many had caused them to become impotent. For participants who were married or in romantic relationships, this had changed the dynamic of this relationship. For some, this had caused a decrease in the level of emotional intimacy and non-sexual physical intimacy. For others, the experience of surviving cancer had brought them closer together and increased appreciation for one another, despite the change in their sex life.

Literature investigating sexual functioning in CRC patients, both with and without liver metastases, supports the finding that sexual functioning can be a long-term problem for this population (Rozmovits & Ziebland., 2004; Donovan, Thompson & Hoffe, 2010; Averyt & Nishimoto, 2014; Rees et al., 2014). Decreased sexual arousal, erectile dysfunction, decreased libido and sexual desire, and lack of sexual enjoyment have all been found in CRC survivors (Havenga, Maas, DeRuiter, Welvaart & Trimbos, 2000; Hendren et al., 2005; Sideris et al., 2005; Guren et al., 2005). Sexuality is an integral part of human the human experience, and is tied to gender identity and self-concept (Wilmoth, 2006). Alterations to sexual health can have a profound effect on individuals' QOL and their partners' QOL. If sexual function is compromised, couples may need to renegotiate their romantic roles or their expressions of intimacy (Tierney, 2008). Erectile dysfunction in men is linked to lower self-esteem and has also been shown to lead to emotional and marital tension (Althof, 2002). For individuals who have already experienced a significant health trauma, such as CRC, sexual functioning problems are an additional negative impact of this situation, and may serve as a constant reminder of their experiences. The inability to return to a pre-cancer sex life may have a substantial impact on individuals' identity, both as a partner, and as a man or woman. Adjusting to these changes both on a personal level and as a couple, may pose a significant challenge.

Emotional changes and experiences throughout the cancer journey provided a prolific topic of discussion. Some participants described enduring emotional side-effects of chemotherapy, such as paranoia and fear. Participants talked about feeling 'watched' or that someone had been in their house. Depression and anxiety were two of the most common emotions expressed by participants. Individuals described feeling 'low' and 'sad'. The salience of emotions in daily life also heightened in some participants. They talked about how post-cancer they experienced unexplainable surges of emotion or that their emotional threshold was much lower. Others described fears of recurrence and a continual worry that the cancer would come back. During discussions about how the experience had affected them emotionally, participants also talked about feeling conflicted. It was clear that many still experienced challenging and often negative emotions as a result of their experiences, yet they felt guilty in having these emotions as they had survived where as many others with the same condition had not.

The emotional experience of long-term cancer survivors has received little attention in the literature to date. The majority of work in this area has focused on the early course of the illness and the experiences of diagnosis and treatment (Mitchell, Ferguson, Gill, Paul & Symonds., 2013). However, the current recognition that cancer is more akin to a chronic rather than an acute condition has meant that there is an increasing interest in the on-going emotional impact of these experiences. Longitudinal work on anxiety and depression in cancer survivors has shown that the level of mood disturbances falls with time, yet remain higher than in healthy controls (Korfage, Essink-Bot, Janssens, Schroder & de Koning, 2006; Burgess et al., 2005). Cancer-related health worries have been shown to be a significant predictor of both anxiety and depression (Deimling et al., 2006). Some of these concerns may be due to a lack of understanding about what caused their initial cancer. Many participants in this study articulated dissatisfaction with the medical explanation for their cancer, and concern that if they did not know the cause then they did not know how to avoid another tumour in the future.

Some work investigating long-term cancer QOL has shown that the emotional experiences of cancer patients can be linked to post-traumatic stress disorder (Smith, Redd, Peyser & Vogl, 1999). This can include feelings of anxiety and emotional distress, nightmares and flashbacks, fear, anger and irritability, and feelings of guilt and shame. Feelings of guilt and shame may also be tied to 'survivor guilt'. Survivor guilt refers to the feelings of guilt experienced by surviving an event that others did not; it is commonly used in relation to war, natural disasters or accidents. Many participants in this study articulated that they did not feel or perceive themselves as the 'typical cancer patient'. They talked about not feeling or looking ill enough to merit being this label. One even described herself as a 'fraud'.

It is important to note that not all emotional impacts were described as being negative. In addition to highlighting the emotional challenges they experienced, participants also talked about positive aspects of their emotional developed as a result of their cancer. For some, surviving cancer had been a catalyst for becoming more empathetic and understanding of others. Words such as 'compassion', 'considerate' and 'sympathetic' were commonly used. Literature on post-traumatic growth has shown that experience cancer can cause positive life changes such as strengthened relationships and compassion for others (Morris, Shakespeare-Finch & Scott, 2012). This is often described as an increased awareness of others' experiences and a desire to help other people (Hefferson, Grealy & Mutrie, 2009). Participants in this study not only described having more patience for others, but also doing more within their community to help others, such as charity work or helping elderly neighbours.

As well as intrapersonal changes impacting on participants' QOL, their views on what QOL meant to them and their perspective on life had also changed. Some participants discussed changes in their life priorities and how the experience had caused them to reevaluate their life. Participants talked about being more relaxed about life and appreciating what they had; others talked about valuing their family and friends. This was primarily attributed to the increased saliency of their own mortality and feeling lucky and grateful to still be alive. Due to their experience of mortality and death, their forward planning and worries about the future had also changed. Many reported altered perceptions of time and that they no longer looked far into the future, but rather tried to enjoy the present. Changes in life views and priorities are by no means new findings in cancer research. Many studies have shown that cancer survivors report an increased appreciation for life, family, friends, and self (Charles, Sellick, Montesanto & Mohide, 1996; Dirksen, 1995; Ferrans, 1994; Ganz et al., 1996, 1998; Kennedy, Tellegen, Kennedy & Havernick, 1976; Wyatt, Kurtz & Liken, 1993). A study on breast cancer survivors reported very similar findings to this study. Ganz et al. (1996) described how women talked about only thinking in shorter increments of time and not postponing any important plans. Appreciation of self and experiencing more enriched relationships with friends and family were also reported.

Positive framing of cancer experiences may be an important and effective coping mechanism. Experiencing a life-threatening disease is a hugely distressing event for both the individual themselves, and their family and friends. CRC patients with liver metastases face extremely low survival chances, and may be left with life-altering physical changes. Even if the long-term physical impact is low, the emotional trauma of going through such an experience will still remain, with individuals often finding it hard to rationalise why this has happened to them. Many of our assumptions about the world are based on the idealised notion that good things happen to good people, and bad things happen to bad people (Lerner, 1980). However cancer knows no such discrimination. These thoughts can also be linked to an undermined feeling of invulnerability and increased victimisation. The majority of people report feeling a sense of control over their life and the events that happen to them (Taylor & Brown, 1988), whereas experiencing cancer fundamentally undermines this belief. Work on adjustment to cancer suggests that looking for positive meaning and outcomes after cancer survival may be an important step for cancer survivors (Tomich & Helgeson, 2002). Finding meaning after traumatic events is associated with lower psychological distress, greater social adjustment, and higher self-esteem (Silver, Boon & Stones 1983; Thompson, 1991). By focusing on the positive outcomes of their cancer, participants in this study may be reframing their experiences in order to deal with the trauma of this event.

Previous literature has illustrated that a search for meaning is an important part of the cancer experience (e.g. Taylor, 1995; Park, Edmondson, Fenster & Blank, 2008; Lee, 2008). It has been suggested that individuals possess 'life schemas' or models of reality that help them to feel a sense of order, coherence and purpose throughout their life. These schemas act much like the plot of a play or story which organise individuals' perspectives on the world, the values they hold, and goals they may wish to achieve in relation to the events which occur throughout their life. This general feeling that one's life has purpose and meaning is also linked with QOL (Lee, 2008). When a severely negative event happens, such as being diagnosed with cancer, an individual's sense of order and control is disrupted and replaced with feelings of disorder, randomness, helplessness and distress (Taylor, 1995). This can be termed as 'existential plight' (Weisman & Worden, 1976). The ensuing search for meaning is a normative process in which people seek to understand what has happened to them and appraise the impact that their cancer has had on their lives. Those individuals who successfully find meaning in the cancer, often report greater self-awareness, personal growth, appreciation for life, and compassion for others (Lee, Cohen, Edgar, Laizner & Gagon, 2004; Taylor, 2000); findings which resonate strongly with the current study. From a clinical perspective, supporting cancer patients in their search for meaning could help to mediate cancer-related distress and psychological wellbeing. Indeed, cancer patients often turn to medical professionals in order to make sense of their experiences, as evidenced in the results of this study. In order to provide this support, health care professionals need to understand the processes patients engage in in their search for meaning, and how best to support them in this journey.

Turning to religion or the emergence of newfound religious beliefs may also be a method of finding meaning and purpose in traumatic experiences. A number of participants in this study recounted the importance of their religious beliefs in helping them through the experience and as their main source of emotional comfort. One participant talked about finding religion as a result of her cancer. Spiritual well-being has been shown to be an important source of support for cancer survivors and their families (Kuuppelomaki, 2002; Taylor, 2003). In addition, there is growing a consensus that spiritual well-being may help to heighten psychological functioning and promote positive adjustment to illness (McCain et al., 2003). This construct is also linked to better psychosocial adjustment and lower levels of depression (O'Mahony, Blank, Zallman & Selwyn, 2005; Krupski et al., 2006; Rippentrop, Altmaier & Burns, 2006; McCroubie & Davies, 2006). Previous research on CRC survivors has shown that spiritual well-being has strong direct effects on HRQL and it has been suggested that a biopsychosocial-spiritual model of HRQL may offer additional insights into patient experience (Bulkley et al., 2013; Puchalski et al., 2009). Religious and spiritual beliefs may serve as an additional process of finding meaning in a seemingly

meaningless event and help to cope with uncertainty of outcome. Although participants in this study were now all classed as in remission, those with strong religious or spiritual beliefs all talked about feeling comforted by the hope and peace of mind this gave them. Some also talked about this in terms of facing their own mortality. Having beliefs about the after-life meant that their fear of dying was lessened; even though all expressed strong attitudes regarding survival and determination to beat the cancer, they found comfort in the fact that, to them, death was not the end.

Besides having intrapersonal benefits, religious beliefs offer an additional source of social support within Churches or other organised groups. Participants in this study reported solely Christian beliefs and many talked about their extended circle of support through the church community. Discussion around this source of support elicited reports of feeling looked after and of being understood. Social networks can offer different aspects of support to cancer survivors. Social support, which can be offered in a number of ways including practical, emotional and informational, can increase individuals' self-esteem and improve coping strategies and skills in times of stress (Bloom & Spiegel, 1984; Bloom, 1982; Irvine, Brown, Crooks, Roberts & Browne, 1991). For example, a study of female CRC survivors in the US found that having larger social networks and greater social connectedness was positively associated with mental health (Sapp et al., 2003). Social networks can also offer support via social influence and behavioural norms. If members of an individuals' social network are keeping active, socialising or seeking emotional support from other members, then it is more likely that an individual undergoing a difficult or traumatic event may do the same (Breslow & Breslow, 1993). One participant in the current study talked about how having a social network through his dance classes meant that he was able to stay active and renew his social activities after his cancer treatment.

## **Aim 2: To explore survivorship experiences in CRC survivors 5 years post-surgery**

The definition and usage of the term 'survivorship' varies across the literature. In some studies the term is used in a temporal sense to denote individuals who are at least 5 years post-treatment. In other work, it is aligned with personal identity (Deimling et al., 2007). In this study, no definition of survivorship was given to participants; they were simply asked if they felt like a cancer survivor.



Within the results, dualistic responses were identified. Some participants talked at great length about survivorship and what this meant to them, whereas others felt the term did not apply to them. The rejection of the term 'survivor' or 'survivorship' by some may be due to several reasons. One simple reason may be that some participants felt their cancer had had only a minimal impact on their lives. Participants talked about carrying on as if it had never happened, or giving the disease a similar significance to that of having a cold. For others, the reason for not identifying as a survivor may be that they felt they did not deserve this term. During the interviews, participants talked about what a 'cancer patient' should be like and/or look like. A key thread throughout these discussions was that their own experiences did fit with their own preconceptions about what having cancer would be like. They had not looked or felt ill enough. In addition to this, they felt their survival was due to luck or chance. They had not done anything special to survive compared to others who had not, and indeed many expressed a lack of understanding about this. Previous work on survivorship in breast cancer patients found that some women in this study felt the term 'survivor' to be overly heroic and that they did not feel their experience had been severe enough to merit this title (Kaiser, 2008). In addition, 'survivor' implies that there is no chance of the cancer recurring, something that participants actively worried about.

For those that did identify with survivorship, this mainly referred to changes in post-cancer identity and view of the self. Participants described a post-cancer self that had a renewed appreciation for life, enriched social relationships, and greater empathy and understanding for others. As mentioned above, it could be argued that these changes in identity and viewpoints are a form of post-traumatic growth. This phenomenon refers to positive changes which occur as a result of undergoing a traumatic experience, such as cancer. It is not a natural process of personal development (Zoellner & Maercker, 2006), but can better be understood as the process of putting back together or resetting the pieces of self that were shattered as a result of the trauma and finding meaning from the experience (Thornton & Perez, 2006). Models supporting post-traumatic growth posit the idea that experiencing a trauma changes the internal schema of an individual's world view, .i.e. the way they see the world, self, and others, as also discussed in relation to existential plight and search for meaning (Weisman & Worden, 1976). Within the literature, post-traumatic growth has been subdivided into 3 main components: 1. Perceived changes in self; 2. Changes in interpersonal relationships; and 3. Changes in spirituality or the philosophy of life (Tedeschi et al., 1998). If we look at this in comparison to the current study, these processes mirror much of the participant experience and discussion around the changes that had occurred as a result of their cancer.

Despite the growth of literature exploring survivorship and post-traumatic growth in cancer patients, this concept is contentious. Alternative views see post-traumatic growth as an illusory mechanism aimed reducing the psychological distress caused by experiencing a traumatic event. Individuals use this as a short term coping strategy to preserve self-esteem and maintain a sense of control (Sumalla, E.C., Ochoa, C. & Blanco, 2009). Many participants experienced drastic changes in their lives, such as the loss of their job, severely decreased physical ability, significant reduction in sexual function, and a new reliance on their family, partner or friends. These changes can have a profound impact on personal identity. For example, a participant may go from being a competent working member of society with a senior job role, and a virile male with a healthy sex life, to no longer working, unable to fulfil the same romantic role, and increasingly reliant on others for self-care. From this perspective, post-traumatic growth serves as a buffering mechanism to preserve identity.

Several theories suggest that post-traumatic growth is a form of cognitive reframing which helps individuals make sense of their experiences. Temporal comparison theory (Albert, 1977) seeks to explain how individuals deal with traumas or periods of crisis. This theory is based on the notion that people need to maintain a sense of stability and continuity within their lives, despite the presence of potentially life altering events. This is particularly pertinent in regards to identity and sense of self. In order to make sense of traumatic events which endanger one's sense of self and identity and to gain a greater sense of control, individuals can distort their views of their pre-trauma self in order to come to terms with these changes. As a rule, individuals perceive their pre-cancer self and experiences as more negative than they actually were, and by doing so are able to see themselves and their experiences as improving over time. Not only does this help them to feel more in control of their situation, but it also allows them to make sense of events that have no logical cause. An alternative view is given by Cognitive Adaptation Theory (Taylor, 1983). This theory offers an explanation of the process of psychological readjustment that occurs when individuals experience a traumatic event which threatens personal integrity. Taylor postulates that this encompasses three main strategies: 1. a quest for meaning in adverse events; 2. an attempt to keep at least a minimum level of perceived control over one's life; and 3. an effort to increase the sense of value and self-esteem. These mechanisms not only help to serve as a buffer against present threats, but also the fear of future setbacks such as the recurrence of disease.

Both of these theories find their roots in Festinger's theory of social comparison. Therefore it is possible that process of identity change and mental reframing at the heart of these theories is a form of cognitive dissonance (Festinger, 1957). As many aspects of individuals' pre-cancer identity is limited or taken away as a result of cancer treatment, (e.g. such as work life, physical ability,

engagement in hobbies), a disparity is created between the individuals' understanding of their pre-cancer self and their current status. In order to cope with these changes, individuals shift their self-concept and identity to fit around their new 'cancer-self', and rather than focusing on the negative side of these changes, instead incorporate them into a new 'survivor identity'.

In regard to the results of the current study, these theories offer an insightful lens through which to make sense of participants' stories. Participants often discussed feeling that they had experienced personal growth and positive gains as a result of their experiences of cancer, despite experiencing on-going negative physical and emotional impacts. Many individuals talked about their need to find an explanation as to why this had happened to them. Some turned to memories of past physical trauma or certain events that may have triggered the start of their cancer. Others turned to their religious beliefs as a way of coping with uncertainty and of regaining meaning and stability in their lives. Both viewpoints of post-traumatic growth, as a real phenomenon or an illusion, have merit and theoretical underpinnings. However an alternative suggestion is that these changes may start out as a coping mechanism to preserve identity, self-esteem, and control, but over time become real and are adopted as a core part of identity and self. However it should also be remembered that these changes are not relevant for all cancer survivors. Many do not identify with survivorship in the same manner and see no real changes in their lives as a result of their experiences. From this study is not clear why this might be or if there is a fundamental difference between these two groups, however what is clear is that experiencing cancer is highly subjective and may result in a range of different outcomes with individuals using various strategies of adjustment and coping.

Understanding the adjustment of long-term survivors and the contributory factors which influence this adjustment is important in providing appropriate support. It is clear from the results that individuals use a range of strategies to cope with their cancer and that individual differences in adjustment may have a significant impact on patients' psychological outcomes and wellbeing. A predisposition to resilience or optimism may result in better adjustment to the long-term impacts of CRC, whereas patients who are predisposed to depression and anxiety may experience more negative outcomes and find it harder to adjust to post-cancer life. The results of this work show that having access to positive social support from family and friends, and finding acceptance and understanding from the wider community were important contributory factors in positive post-cancer adjustment, and in forming a new post-cancer identity. On the other hand, fixation with loss as a result of cancer and negative impacts of the illness were associated with worse psychological outcomes, lower wellbeing, and lower likelihood of forming a positive post-cancer self-identity.

In order to provide support for long-term survivors, health professionals should understand the range of factors that contribute to differing levels of psychological adjustment. Individuals who lack social support may benefit from greater contact with support staff, or from relevant cancer support groups. Being able to share experiences with a group of similar individuals may provide long-term survivors with the acceptance and understanding they lack in their existing social circles. In addition, being able to sign-post individuals who may be at greater risk of poor psychological adjustment may help focus limited resources and tailor support packages to be of most benefit to patients. Using psychological measures of dispositional optimism and resilience early on in treatment could provide greater insight into those individuals who will need a higher level of support in the long-term, in comparison to those who may require less active support strategies.

### **Aim 3: To explore the relevance of the EORTC QLQ-C30 and LMC21 questionnaire domains to this population**

The final aim of this study was to explore whether the EORTC QLQ-C30 and LMC21 were relevant to the participants, and whether additional areas may be important to consider.

The negative impacts of on-going bowel problems and reduced sexual function are supported by previous quantitative work with this participant group. Rees et al.'s 2014 paper using the same cohort of patients showed decreased sexual function and on-going bowel issues at 5 years post-surgery, measured using the EORTC QLQ-C30 and LM21 quality of life questionnaires. However, Rees et al. also reported higher emotional, social and role functioning scores compared to baseline; a finding not fully supported by the current study. Baseline data for the patients in Rees et al.'s study were recorded at least 4 weeks prior to surgery. At this time point patients would have received a diagnosis of cancer, been told the stage and survival chances, and likely have discussed a treatment plan. Previous literature on experiences of cancer diagnosis clearly demonstrates that this is emotionally a very distressing time for individuals (Burgess, Morris & Pettingale, 1988; Stanton & Snider, 1993; Jim, Richardson, Golden-Kreutz & Anderson, 2006). Therefore arguably these data do not give an accurate representation of pre-cancer baseline QOL, but rather a picture of post-diagnosis QOL. In this case it comes as no surprise that patients in remission will have better emotional wellbeing than after being told they have potentially terminal cancer and at a time when they are facing highly stressful regimes of surgical and/or chemotherapy and radiation treatment with no guarantee of survival.

Questions on social and emotional experiences within the EORTC questionnaires are also framed in a reductive manner and only ask about a very narrow range of experiences such as the presence or absence contact with friends, or talking to friends or family about their feelings (for full items see appendix 1). From the results of the current study, it is clear that the picture is much more complex. Many patients experienced positive gains both on an intrapersonal and interpersonal level. Additionally, the results show that the emotional impact of cancer is far from linear. Whilst patients may experience joy and happiness in survival and renewed appreciation for this, they can also experience survival guilt and fear of recurrence. As well as the type of affect being of importance, the change in salience of various emotions was also clear. Participants talked about becoming more emotional as individuals, experiencing unexplained waves of emotion or in being increasingly sensitive to external stimuli.

Aside from bowel issues and sexual function, at the time of this study the majority of the EORTC QOL items were no longer relevant to participants. The EORTC QLQ-C30 and LMC21 questionnaires were developed to measure short-term QOL, and have a primary focus on physical symptoms. Although participants did mention some on-going physical concerns, the main discussions centred on coming to terms with their cancer and how they had coped with these experiences and adapted to their new post-cancer lives. Coping strategies such as maintaining a positive mental attitude, reframing life focus, and religious and spiritual beliefs were highly important to these individuals. Living with cancer and adapting to the person they had become as a result of their cancer was an on-going experience.

The EORTC QLQ-C30 and LMC21 QOL measures do not address the issues of survivorship or post-cancer identity change. The results of this study suggest that these two concepts are not disparate, but instead are related to one another. Individuals who experience cancer use various coping strategies to deal with the trauma. Some of these are tied to changes in self and identity, and the formation of a new post-cancer self, others focus on a search for meaning. This can include a shift in life priorities, greater importance placed on social relationships, increased empathy for others, and intrapersonal changes. It can be argued that these changes will have a direct impact on how these individuals define QOL and what having a high QOL means to them. Whereas pre-cancer their physical health or work life may have been of paramount importance, experience a life-threatening event may cause this to change. Future studies of QOL within this population and cancer survivors as a whole must recognise that individuals' definitions of QOL may change as a result of their experiences. Thus the pre-cancer measures of QOL may no longer be relevant.

## **What are the implications for how QOL is measured and defined within this population?**

Previous work exploring QOL in CRC survivors with liver metastases has primarily utilised HRQL measures focused on symptoms, physical health, and negative emotional and social impacts. The focus of these measures and investigations is on deviation from a healthy norm and levels of negative changes relative to a pre-surgery baseline. In comparing these measures to the results of the current study, it is clear that they do not capture the full patient experience.

The results of this study show that life priorities and important aspects of participants' lives change over time and as a result of their experience of cancer. Many discuss having a different life focus compared to pre-diagnosis or even pre-surgery. Current quantitative QOL measures use a pre-treatment baseline in order to compare changes in QOL post-treatment. The changes in scores are based on the assumption that the saliency of each domain in assessing overall QOL will remain the same during the treatment and recovery process. As previously discussed, although an argument can be made for a core set of QOL dimensions, the relative importance of each dimension may vary between individuals and also over time (Felce, 1997). Individuals have different ideas of what constitutes a 'good quality of life' and what it means to be happy and fulfilled. Experiencing a serious health trauma may be a catalyst for a shift in these ideas (Sprangers & Schwartz, 1999). Therefore, the items and domains measured pre-surgery, may carry very different weighting post-surgery. For long-term cancer survivors there may be further shifts which occur in the years after treatment as they adjust to their new lives. If this is the case, objective quantitative questionnaire measures of QOL will fall short of capturing the changes that occur in the relative saliency of dimensions as well as within dimensions.

Two symptoms commonly explored in QOL measures for CRC patients with liver metastases are bowel issues and sex life. In line with the findings of the current study, previous quantitative studies have found that CRC survivors with liver metastases experience on-going bowel issues and decreased sexual function. Whilst this is an important finding for providing appropriate patient support and informing patient expectation, quantitative measures offer no insight into what impact this has on individuals' lives. For some participants in the study, changes in their sex lives negatively impacted on their relationship with their partner, for example through a decrease in emotional intimacy and satisfaction. For others, going through the experience had brought them closer together and increased emotional connectedness and intimacy, despite a decrease in sexual function and activity. These results show that a change in sex life scores on a quantitative

measure is only telling half the story. What may be of more importance is the adjustment to these changes and the on-going impact it has on individuals' lives. The degree of change in adjustment to physical changes is not necessarily linked to the severity of those changes. Literature on visible differences has shown that it is not the severity of the condition, but how an individual perceives and adjusts to it that determines the overall impact (Moss, 2005; Ong et al., 2007; Feragen et al., 2010; Brown et al., 2010). Current QOL measures do not include questions on adjustment to these changes, but only include items exploring whether a change has occurred.

These results are also tied to a wider finding regarding the variation in experience and contradictions between different participant accounts. The results of this study are by no means homogenous and clear-cut; there is contradiction and deviation between participant accounts, and also within individual stories. This is particularly true in relation to emotional impacts. Some participants reported experiencing on going negative emotions and changes in emotional reactions and sensitivity, whilst others primarily discussed positive changes such as increases in empathy and understanding. Even within individual accounts, many different emotional changes were discussed. Feelings of joy and gratefulness for being alive were also tinged with guilt for surviving when others did not. The complexity of these experiences calls into question whether objective measures of QOL can ever offer a complete insight into these patients' adjustment to their condition.

One of the criticisms of current QOL measures is the focus on reduction and limitation rather than on positive gains. It is clear from the results of this study that participants do experience on-going limitations and negative impacts from their cancer; however the results also show that participants discuss many positive outcomes and changes as a result of their experiences. The results support previous reports of renewed appreciation for life, increased compassion and empathy, and increased personal resilience (Danoff et al., 1983; Fromm et al., 1996; Taylor et al., 1984; Tempelaar et al., 1989). Given these results, current QOL measures, and particularly HRQL measures, appear deficient in their focus. The narrow concentration on a predefined set of dimensions leaves no room for items relating to personal growth or additional positive gains which may not have been previously present. None of the most commonly used measures for this patient group (including the EORTC-QLQ C30, LMC21 or EQ-5D) contain any items on life focus, life priorities, or positive changes. Items are phrased in a language of deficit with questions asking about reductions in various physical, social or emotional abilities. Given that literature on post-traumatic growth after cancer is becoming increasingly prevalent, and the growing inclusion of survivorship services within current healthcare, the lack of questions regarding these changes in QOL measures can be seen as a serious shortfall.

As previously discussed, there is an on-going debate regarding whether QOL is an objective or subjective phenomena. Current QOL measures have been predominantly developed from a positivistic framework using a discrete set of quantitative domains. In addition to this, objective models often use health status as a proxy for QOL with a focus on reduction or deviation from a healthy norm. These HRQL measures posit a scenario where individuals experiencing on-going physical issues, such as bowel problems or decreased sexual function, can never achieve a high quality of life. However as we have seen in this study, this is not the case. The results from this study show that QOL is a highly subjective experience and can change over time and as a result of experiencing a serious health trauma. Given these findings, the question arises as how to how these subjective experiences should be measured.

Rather than seeking to develop a universal measure of QOL, it may first be more important to understand why we are seeking to measure it. For example, are we seeking to understand patient experience, or are we seeking to understand how the disease and treatment will affect physical health? QOL measures in health research are often used as they are purported to provide an ongoing picture of patient recovery, disease trajectory, and the short-term impact treatment. These measures can then provide important information on the suitability of different treatment approaches, and can inform treatment decision-making. In these cases, objective HRQOL measures can have an important role to play, particularly in the short-term as at this time patients may be more concerned with their physical health and likely recovery time.

HRQOL measures do then play an important part in understanding patient experience and can be valuable source of information in relation to the short-term impacts, however it cannot be claimed that they provide the whole picture. This study illustrates that QOL is a much more holistic concept, and is not necessarily dependent on physical health. As QOL can change over time and as a result of health trauma, it seems short-sighted that the same QOL measure and domains used at diagnosis, treatment, and short-term recovery, will be appropriate or even relevant when assessing the longer-term. Survivorship and post-cancer identity can become a much more pertinent focus for many long-term cancer survivors. Whether this is due to the implementation of coping strategies to maintain internal integrity, or through genuine personal transformation, the fact that these changes are believed by patients to occur is incredibly important. For these long-term survivors, the more relevant questions may centre on adjustment and how their life perceptions have changed.

In working to understand the full picture of QOL and how it may change over time for cancer patients, a mixed methods approach may be of benefit. The mixed methods approach recognises



that there are many ways of making sense of the world and understanding experiences, and additionally that different standpoints on what is important or valuable are equally valid (Greene, 2008). Previous work exploring the utility of mixed methods work in health research suggests that this approach can offer an insight into individual experiences within a 'real world' context (Dures, Rumsey & Morris 2010). Through adopting a flexible and pragmatist approach to health research, mixed methods work recognises the clinical context of research and the wider healthcare system needs and agendas, whilst still allowing for the exploration of new ideas and experiences. In chronic conditions, such as cancer, this approach could then allow for the quantitative measurement of treatment burden, symptoms, and HRQOL, whilst still recognising the importance of qualitative enquiry in further understanding the patient experience.

## **Clinical implications**

From a clinical perspective, these findings provide valuable information to both health professionals and future patients. As cancer is being increasingly recognised as a chronic rather than acute condition, so the needs of cancer patients should be considered in the long-term and not just during the initial treatment and recovery period. Whilst quantitative measures such as the EORTC-QLQ-C30 and LMC21 questionnaires can offer valuable information on the short-term impact of treatment for CRC cancer patients with liver metastases, the content is not suitable or relevant for long-term survivors. In order to fully understand the experiences of long-term survivors and provide appropriate on-going support, it is important to recognise that some individuals may experience on-going emotional distress and undergo profound personal changes. One of most striking messages from these results is the importance of mental framing. Mental framing of cancer can offer a valuable coping strategy for adjusting to the long-term impacts of cancer. Through keeping a positive mind-set and mental attitude, participants were able to cope with very distressing consequences of their cancer. In addition, many discussed experiencing post-traumatic growth and the search for meaning. Although the mechanisms of these changes are still not clear, using positive mental framing can help cancer survivors to positively adjust to life after cancer. Making health professionals aware of these changes and the cognitive processes that cancer patients may undergo could help them to offer better support and advice to long-term survivors, and also help to prepare patients who are in the early stages of their cancer journey.

The additional use of measures to assess levels of resilience may also help to signpost which patients will be in need of greater long-term psychological support. If positive mental framing acts as successful coping mechanism and psychological buffer, those individuals who possess these characteristics may experience less trauma and therefore require less psychological support. In contrast, those with lower dispositional optimism may find it more challenging to enact these

strategies and be at high risk for emotional distress and long-term psychological trauma. By assessing resilience levels early on in the treatment process, health professionals can firstly identify high risk patients, and secondly tailor their support to better suit the individual (Lam, 2010).

The understanding that experiencing cancer is an extremely holistic experience demonstrates that cancer survivors may benefit from a wider range of professional support and expertise. Health Psychologists could offer a valuable bridge between body and mind. Whilst surgeons and other medical professionals can offer advice and expertise on physical health, Health Psychology offers further insight and understanding into how physical health affects mental wellbeing. As long-term cancer QOL and survivorship appears to entail an on-going relationship between how the physical impacts affect mental wellbeing, and how mental framing can affect adjustment to physical changes and health, Health Psychology could offer an important role in on-going care.

The findings of the current study could also be of benefit to advancements in the survivorship agenda through the work of initiatives such as the Living With and Beyond Cancer Programme (2014) being run in collaboration between NHS England and Macmillan Cancer. As the aim of this initiative is the embedding of survivorship support within NHS commissioning and service provision, these findings could provide an evidence base for the ongoing needs of cancer survivors and the importance of providing a holistic care package.

## **Limitations and future directions**

One of the primary limitations of this study is the sample. The sample was primarily composed of Caucasian participants, with little ethnic or socio-economic diversity. In addition the sample contained only 5 women. Due to the location of CRC, it is likely that some of the issues patients' experiences are highly gendered. Although a second round of recruitment did increase the number of female participants, a greater balance between genders would have been beneficial. However, due to the sampling restrictions this may not have been possible in the current study. All women who expressed an interest in taking part in the qualitative work were contacted, therefore in order to recruit more women the study would need to have recruited participants from beyond the existing cohort. Minimal gender differences were found in the overarching experiences of participants, however there were differing reports concerning the emotional impact, types of social support, and romantic relationships. Female participants were more likely to talk in depth about the emotional impact of their cancer, and their emotional struggles, whereas the male participants had a stronger focus on practical impacts. Whether this is due to actual differences in experience, or differences in disclosures it is not clear; as discussed in the

reflective chapter, women are often more used to discussing their emotions and emotional needs, whereas at a societal level men may find it less acceptable to discuss these issues openly and therefore be less likely to disclose this during an interview. Men and women also reported different impacts on sexual function and romantic relationships. The sexual function of women seemed unaffected whereas the majority of men had experienced significant sexual limitations as a result of their cancer.

The chosen analysis for this study was inductive thematic analysis, as described by Braun and Clarke (2013). This method was chosen as it offers insight in patterns and themes across the dataset, and it guided by a bottom-up data-driven approach. Whilst it can offer valuable insights into new topics and is appropriate for exploratory research guided at increasing understanding, it does lack interpretive power and can lose sight of the individual nuances of participants' stories. This research may have benefited from the addition of some case studies of individual participant stories. This would enable the research to highlight the discrepancies and contradictions within individual accounts, and provide greater depth to the results.

Future work could profit from a Grounded Theory approach (Glaser & Strauss, 1965). Grounded Theory offers a method of exploring the 'why' of research as well as the 'what'. Grounded theory is an approach to both data collection and analysis concerned with constructing a theory from the data. This type of qualitative research can be used to further understand psychological processes that underpin a particular phenomenon (Charmaz, 2006). This could offer greater insight into the mechanism of post-traumatic growth, search for meaning, identity change, and the changes in the salience of QOL dimensions. The current study has offered a new knowledge regarding the experiences of long-term CRC survivors with liver metastases, but it does not offer any explanation as to why or how these experiences occur. In order to further develop this work, future qualitative studies could use Grounded Theory to build a more comprehensive picture of the psychological processes that individuals go through, and the influencing factors for these processes.

## **Conclusion**

In conclusion, this study has shown that CRC survivors with liver metastases define QOL in different ways, and have a broad and diverse range of experiences. For these long-term cancer survivors, the physical symptoms that were salient in the short-term cease to be the main focus of their attention. Instead, their relationship with cancer, developing coping strategies, and coming to terms with their post-cancer self are of far more importance. As QOL is a subjective experience, there is no 'one size fits all' approach to definition and measurement. Health care professionals

and policy makers need to understand the variety in meaning and be clear about the purpose of QOL measures. In attempts to promote long-term positive adjustment, cancer survivors may benefit from a wider range of support and expertise. Health Psychologists in particular could offer valuable insight and support in relation to adaptive coping strategies, mental framing, adjustment to physical changes, and the development and adjustment to the 'post-cancer self'. Future work would benefit from holistic definition of QOL and from using a broad range of assessment techniques.

## References

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- Albert, S. (1977). Temporal Comparison Theory, *Psychological Review*, 84(6): 485-503
- Albrecht, G.L. & Devlieger, P.J. (1999). The disability paradox: high quality of life against all odds, *Social Science and Medicine*, 48: 977-988
- Albrecht, G.L. & Devlieger, P.J. (1999). The disability paradox: high quality of life against all odds. *Social Science and Medicine*, 48(8): 977-988
- Althof, S.E. (2002). Quality of life and erectile dysfunction, *Urology*, 59:803-810.
- Appleton, L., Goodlad, S., Irvine, F., Poole, H. & Wall, C. (2013). Patients' experiences of living beyond colorectal cancer: A qualitative study, *European Journal of Oncology Nursing*, 17: 610-617
- Arendell, T. (1997). Reflections on the researcher-researched relationship: A woman interviewing men, *Qualitative Sociology*, 20(3): 341-368
- Averyt, J.C. & Nishimoto, P.W. (2014). Psychosocial issues in colorectal cancer survivorship: the top ten questions patients may not be asking, *Journal of Gastrointestinal Oncology*, 5(5): 395-400
- Averyt, J.C. & Nishimoto, P.W., (2014). Addressing sexual dysfunction in colorectal cancer survivorship care, *Journal of Gastrointestinal Oncology*, 5(5):338-394
- Bakas, T., McLennon, S., Carpenter, J.S., Buelow, J.M., Otte, J.L., Hanna, K.M., Ellett, M.L., Hadler, A. & Welch, J.L. (2012). Systematic review of health-related quality of life models, *Health and Quality of Life Outcomes*, 10: 134-
- Baker, S. E. & Edwards, R. (2012) *How many qualitative interviews is enough? Expert voices and early career reflections on sampling and cases in qualitative research*. Southampton: ESRC National Centre for Research Methods, University of Southampton.
- Banz, V.M., Inderbitzin, D., Fankhauser, R., Studer, P. & Candinas, D. (2009). Long-term quality of life after hepatic resection: health is not simply the absence of disease, *World Journal of Surgery*, 33(7):1473-80
- Bhaskar, R. (1989). *Reclaiming reality*, Verso: London
- Blazeby, J.M., Avery, K., Sprangers, M., Pikhart, H., Fayers, P., Donovan, J. (2006). Health-related quality of life measurement in randomized clinical trials in surgical oncology. *Journal of Clinical Oncology*, 24(19):3178-86.
- Blazeby, J.M., Greimel, E., European Organisation for Research and Treatment of Cancer (EORTC) Data Centre and Quality of Life Group. (2005). Health related quality of life outcomes in cancer clinical trials. *European Journal of Cancer*, 41(12):1697-709.
- Blazer D.G., Kishi, Y., Maru, D.M., Kopetz, S., Chun, Y.S., Overman, M.J., Fogelman, D., Eng, C., Chang, D.Z., Wang, H., Zorzi, D., Ribero, D., Ellis, L.M., Glover, K.Y., Wolff, R.A., Curley, S.A., Abdalla, E.K & Vauthey, J.N. (2008). Pathologic response to preoperative chemotherapy: a new outcome end point after resection of hepatic colorectal metastases, *Journal of Clinical Oncology*, 26(33), 5344-51

- Bloom, J.R. (1982). Social support, accommodation to stress and adjustment to breast cancer, *Social Science Medicine*, 16: 1329-1338.
- Bloom, J.R. & Spiegel, D. (1984). The relationship of two dimensions of social support to the psychological well-being and social functioning of women with advanced breast cancer, *Social Science Medicine*, 19: 831-837
- Bottomley, A., Fletcher, H., Efficace, F., Vanvoorden, V., Coens, C., Therasse, P. & Velikova G. (2005) Health related quality of life outcomes in cancer clinical trials, *European Journal of Cancer*, 41(12): 1697-709
- Bracken, S. (2010) Discussing the Importance of Ontology and Epistemology Awareness in Practitioner Research, *Worcester Journal of Learning and Teaching*, 4: 1-9
- Braun, V. & Clarke, V. (2013). *Successful qualitative research: a practical guide for beginners*, Sage Publications: London
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology, *Qualitative Research in Psychology*, 3: 77-101
- Breslow, L. & Breslow N. (1993). Health practices and disability: some evidence from Alameda County, *Preventive Medicine*, 22: 86-95.
- Broom, A. (2004). Prostate cancer and masculinity in an Australian society: A case of stolen identity? *International Journal of Men's Health*, 3(2):73-91
- Broom, A., Hand, K. & Tovey, P. (2009). The role of gender, environment and individual biography in shaping qualitative interview data, *International Journal of Social Research Methodology*, 12(1): 51-65
- Brown, B., Moss, T., McGrouther, D. & Bayat, A. (2010). Skin scar pre-conceptions must be challenged: Importance of self-perception in skin scarring, *Journal of Plastic, Reconstructive and Aesthetic Surgery*, 63, 1022-1029
- Bulkley, J., McMullen, K., Hornbrook, M.C., Grant, M., Altschuler, A., Wendel, C.S. & Krouse, R.S. (2013). Spiritual well-being in long-term colorectal cancer survivors with ostomies, *Psycho-Oncology*, 22: 2513-2521.
- Burgess, C., Cornelius, V., Love, S., Graham, J., Richards, M. & Ramirez. A. (2005). Depression and anxiety in women with early breast cancer: five year observational cohort study, *British Medical Journal*, 330: 702
- Burgess, C., Morris, T. & Pettingale, K.W. (1988). Psychological response to cancer diagnosis – II. Evidence for coping styles (coping styles and cancer diagnosis), *Journal of Psychosomatic Research*, 32(3): 263-272
- Calhoun, L. G., & Tedeschi, R. G. (1999). *Facilitating posttraumatic growth: A clinician's guide*. Lawrence Erlbaum Associates, Inc: Mahwah, NJ
- Calhoun, L. G. & Tedeschi, R. G. (2001). Posttraumatic growth: The positive lessons of loss, In R. A. Neimeyer (Eds), *Meaning reconstruction and the experience of loss* (pp. 157–172). American Psychological Association: Washington, DC

Cancer Research UK (2014) Bowel Cancer and Symptoms

<http://www.cancerresearchuk.org/about-cancer/type/bowel-cancer/about/bowel-cancer-symptoms> [accessed 27/05/15]

Cancer Research UK (2015) Bowel cancer risk factors <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/bowel/riskfactors/> [accessed 27/05/15]

Carr, A.J. & Higginson, I.J. (2001). Are quality of life measures patient centred? *British Medical Journal*, 332: 1357-1360

Carver, C. S., Pozo, C, Harris, S. D., Noriega, V, Scheier, M. R, Robinson, D. S., Ketcham, A. S., Moffat, F. L., Jr., & Clark, K. C. (1993). How coping mediates the effect of optimism on distress: A study of women with early stage breast cancer, *Journal of Personality and Social Psychology*, 65: 375-390

Cella, D. (1998). Quality of Life. In. Holland, J.C. (Ed.), *Psychooncology*, Oxford University Press, New York, pp.1135-1146

Charles, K., Sellick, S.M., Montesanto, B. & Mohide, E.A. (1996). Priorities of cancer survivors regarding psychosocial needs, *Journal of Psychosocial Oncology*, 14: 57-72

Charmaz, K. (2006) *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*, Sage Publications: London

Clarke, P. & Bowling, A. (1989). Observational study of quality of life in NHS nursing homes and a long-stay ward for the elderly. *Ageing and Society*, 9: 123-148

Cohen, F., Kearney, K.A., Zegans, L.S., Kemeny, M.E., Neuhaus, J.M. & Stites, D.P. (1999). Differential immune system changes with acute and persistent stress for optimists vs pessimists, *Brain, Behaviour, and Immunity*, 13(2): 155-174

Cordova, M.J., Cunningham, L.L.C., Carlson, C.R. & Andrykowski, M.A. (2001). Posttraumatic growth following breast cancer: A controlled comparison study, *Health Psychology*, 20(3): 176-185

Cunliffe, A. L. (2011). Crafting qualitative research: Morgan & Smircich 30 years on, *Organizational Research Methods*, 14(4): 647-673

Danoff, B., Kramer, S., Irwin, P. & Gottlieb, A. (1983). Assessment of quality of life in long-term survivors after definitive radiotherapy, *American Journal of Clinical Oncology*, 6, 339-345

Dasgupta, D., Smith, A.B., Hamilton-Burke, W., Prasad, K.R., Toogood, G.J., Velikova, G. & Lodge, J.P. (2008). Quality of life after liver resection for hepatobiliary malignancies, *British Journal of Surgery*, 95(7):845-54

de Haes, J., Curran, D., Young, T., Bottomley, A., Flechtner, H., Aaronson, N., Blazeby, J., Bjordal K., Brandberg, Y., Greimel, E., Maher, J., Sprangers, M., Cull, A. (2000). Quality of life evaluation in oncological clinical trials - the EORTC model. The EORTC Quality of Life Study Group. *European Journal of Cancer*, 36(7):821-5.

de Visser, K.E., Eichten, A., & Coussens, L.M. (2006). Paradoxical roles of the immune system during cancer development, *Nature Reviews: Cancer*, 6: 24-37

Deimling, G.T., Bowman, K.F. & Wagner, L.J. (2007). Cancer survivorship and identity among long-term survivors, *Cancer Investigation*, 25: 758-765

- Denlinger, C.S. & Barsevick, R.N. (2009). The challenges of colorectal cancer survivorship, *Journal of National Comprehensive Cancer Network*, 7(8): 883-894
- Denlinger, C.S. & Engstrom, P.F. (2011). Colorectal cancer survivorship: Movement matters, *Cancer Prevention Research*, 4(4): 502-511
- Denzin, N. K. (2008). The new paradigm dialogs and qualitative inquiry, *International Journal of Qualitative Studies in Education*, 21, 315-325
- Department for Health (2004). *Choosing health: Making healthy choices easier*, London: Department for Health.
- Dirksen, S.R. (1995). Search for meaning in long-term cancer survivors, *Journal of Advanced Nursing*, 21: 628–633
- Donovan, K.A., Thompson, L.M.A. & Hoffe, S.E. (2010). Sexual function in colorectal cancer survivors, *Cancer Control*, 17(1): 44-51
- Dures, E., Rumsey, N. & Morris, M. (2010). Mixed methods in Health Psychology: Theoretical and practical considerations of the third paradigm, *Journal of Health Psychology*, 16(2): 332-341
- Ellingson, L. L. (2008). *Engaging crystallization in qualitative research*. Thousand Oaks, CA: Sage.
- Faul, L.A., Shibata, D., Townsend, I. & Jacobsen, P.B. (2010). Improving survivorship care for patients with colorectal cancer, *Cancer Control*, 17(1): 35-43
- Fayers, P. & Bottomley, A, on behalf of the EORTC Quality of Life Group and of the Quality of Life Unit (2002). Quality of life research within the EORTC—the EORTC QLQ-C30, *European Journal of Cancer*, 38(4): 125-133
- Felce, D. (1997). Defining and applying the concept of quality of life, *Journal of Intellectual Disability Research*, 41 (Part 2), 126-135
- Feragen, K.J.B, Kvaalem, I.L., Rumsey, N. & Borge, A.I.H. (2010). Adolescents with and without a facial difference: The role of friendships and social acceptance in perceptions of appearance and emotional resilience, *Body Image*, 7, 271-279
- Ferrans, C.E. (1994). Quality of life through the eyes of survivors of breast cancer. *Oncology Nursing Forum*, 21: 1645–1651
- Festinger, L. (1957). *A Theory of Cognitive Dissonance*. Stanford, CA: Stanford University Press
- Fitzpatrick, R., Fletcher, A., Gore, S., Jones, D., Spiegelhalter, D. & Cox, D. (1992). Quality of life measures in health care. I.: Applications and issues in assessment, *British Medical Journal*, 305:1074-1077
- Flick, U. (2009). *An introduction to qualitative research, 4<sup>th</sup> Edition*, Sage Publications Ltd: London
- Frith, H. (2000). Focusing on sex: Using focus groups in sex research, *Sexualities*, 3(3): 275-297
- Fromm, K., Andrykowski, M.A. & Hunt, J. (1996). Positive and negative psychosocial sequelae of bone marrow transplantation: implications for quality of life assessment, *Journal of Behavioural Medicine*, 19, 221-240



- Ganz, P.A., Rowland, J.H., Desmond, K., Meyerowitz, B.E. & Wyatt, G.E. (1998). Life after breast cancer: Understanding women's health-related quality of life and sexual functioning, *Journal of Clinical Oncology*, 16: 501–514
- Ganz, P.A., Coscarelli, A., Fred, C., Kahn, B., Polinsky, M.L. & Petersen, L. (1996). Breast cancer survivors: psychosocial concerns and quality of life, *Breast Cancer Research and Treatment*, 38: 183-199.
- Garssen, B. (2004). Psychological factors and cancer development: Evidence after 30 years of research, *Clinical Psychology Review*, 24(3): 315-338
- Glaser, B. G. & Strauss, A. L. (1965). *Awareness of dying*, Aldine Publishing: Chicago, IL
- Goffman, E. (1974). *Frame analysis, An essay on the organisation of experience*, Northeastern University Press: Boston
- Golafshani, N. (2003). Understanding reliability and validity in qualitative research. *Qualitative Report*, 8, 597-606. Retrieved July 3, 2015 from <http://www.nova.edu/ssss/QR/QR8-4/golafshani.pdf>
- Greene, J. (2008). Is mixed methods social inquiry a distinctive methodology? *Journal of Mixed Methods*, 2: 7–22
- Grief, G.L. & Pabst, M.S. (1988). *Mothers without custody*, Lexington Book: Lexington MA
- Guba, E. G., & Lincoln, Y. S. (2005). Paradigmatic controversies, contradictions, and emerging confluences. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed., pp. 191-216). Thousand Oaks, CA: Sage.
- Guren, M.G., Eriksen, M.T., Wiig, J.N., Carlsen, E., Nesbakken, A., Sigurdsson, H.K., & Wibe, A., Norwegian Rectal Cancer Group. (2005). Quality of life and functional outcome following anterior or abdominoperineal resection for rectal cancer, *European Journal of Surgical Oncology*, 31(7):735-742
- Haas, B.K. (1999). A multidisciplinary concept analysis of quality of life. *Western Journal of Nursing Research*, 21(6): 728-742
- Havenga, K., Maas, C.P., DeRuiter M.C., Welvaart, K. & Trimbos, J.B. (2000). Avoiding long-term disturbance to bladder and sexual function in pelvic surgery, particularly with rectal Cancer, *Seminars in Surgical Oncology*, 18(3):235-243
- Hefferon, K., Grealy, M. & Mutrie, N. (2009). Post-traumatic growth and life threatening physical illness: a systematic review of the qualitative literature, *British Journal of Health Psychology*, 14:343–378
- Heider, F. (1958). *The Psychology of Interpersonal Relations*. Wiley: New York
- Hendren, S.K., O'Connor, B.I., Liu, M., Asano, T., Cohen, Z., Swallow, C.J., MacRae, H.M., Gryge, R. & McLeod, R.S. (2005). Prevalence of male and female sexual dysfunction is high following surgery for rectal cancer, *Annals of Surgery*, 242(2):212-223
- Horgan, O., Holcombe, C. & Salmon, P. (2011). Experiencing positive change after a diagnosis of breast cancer: a grounded analysis, *Psychooncology*, 20(10): 1116-1125

- Huber, M., Knottnerus, J.A., Green, L., van der Horst, H., Jadad, A.R., Kromhout, D., Leonard, B., Lorig, K., Loureiro, M.I., van der Meer, J., Schnabel, P., Smith, R., van Weel, C. & Smid, H. (2011). How should we define health? *British Medical Journal*, 343, d4163
- Imber, J.B. (1986). *Abortion and the private practice of medicine*, Yale University Press: New Haven, CT
- Irvine, D., Brown, B., Crooks, D., Roberts, J. & Browne, G. (1991). Psycho-social adjustment in women with breast cancer, *Cancer*, 67:1097–111
- Jim, H.S., Richardson, S.A., Golden-Kreutz, D.M. & Anderson, B.L. (2006). Strategies used in coping with a cancer diagnosis predict meaning in life for survivors, *Health Psychology*, 25(6): 753-761
- Joffe, H. & Yardley, L. (2004). Content and thematic analysis, In D.F. Marks & L. Yardley (Eds) *Research methods for clinical and health psychology*, Sage publications: London, p. 56-68
- Kaiser, K. (2008). The meaning of the survivor identity for women with breast cancer, *Social Science and Medicine*, 67: 79-87
- Kavadas, V., Blazeby, J.M., Conroy, T., Sezer, O., Holzer, B., Koller, M. & Buckels, J. (2003). Development of and EORTC disease-specific quality of life questionnaire for use in patients with liver metastases from colorectal cancer, *European Journal of Cancer*, 39(9): 1259-1263
- Kelley, H. H. (1967). Attribution theory in social psychology. In D. Levine (Eds), *Nebraska Symposium on Motivation* (Volume 15, pp. 192-238), University of Nebraska Press: Lincoln
- Kennedy, B.J., Tellegen, A., Kennedy, S. Havernick, N. (1976). Psychological response of patients cured of advanced cancer, *Cancer*, 38: 2184–2191
- Khan, N.F., Rose, W. & Evans. (2011). Defining cancer survivorship: a more transparent approach is needed, *Journal of Cancer Survivorship*, 6: 33-36
- King, J.T., Tsevat, J., Lave, J.R. & Roberts, M.S. (2005). Willingness to pay for Quality Adjusted Life Year: Implications for societal health care resource allocation, *Medical Decision Making*, 25: 667-677
- Korfage, I.J., Essink-Bot, M.L., Janssens, A.C., Schröder, F.H., de Koning, H.J. (2006). Anxiety and depression after prostate cancer diagnosis and treatment: 5-year follow-up. *British Journal of Cancer*, 94: 1093–98
- Krupski, T.L., Kwan, L., Fink, A., Sonn, G.A., Maliski, S. & Litwin, M.S. (2006). Spirituality influences health related quality of life in men with prostate cancer, *Psychooncology*, 15:121–131
- Kuuppelomäki, M. (2002). Spiritual support for families of patients with cancer: A pilot study of nursing staff assessments, *Cancer Nursing*, 25(3):209–218
- Lam, W.W.T., Bonanno, G.A., Mancini, A.D., Ho, S., Chan, M., Hung, W.K., Or, A. & Fielding, R. (2010). Trajectories of psychological distress among Chinese women diagnosed with breast cancer, *Psychooncology*, 19: 1044-1051
- Langenhoff, B.S., Krabbe, P.F., Peerenboom, L., Wobbes, T., Ruers, T.J. (2006). Quality of life after surgical treatment of colorectal liver metastases, *British Journal of Surgery*, 93(8):1007-14
- Lee, D. (1997). Interviewing men: Vulnerabilities and dilemmas, *Feminist Research*, 20(4): 553-564

- Lee, V. (2008). The existential plight of cancer: meaning making as a concrete approach to the intangible search for meaning, *Support Care Cancer*, 16: 779-785
- Lee, V., Cohen, S.R., Edgar, L., Laizner, A.M. & Gagnon, A.J. (2004). Clarifying "meaning" in the context of cancer research: a systematic literature review, *Palliative Support Care*, 2:291-303
- Legard, R., Keegan, J. & Ward, K. (2003). In depth interviews, In J. Ritchie & J. Lewis (Eds) *Qualitative Research Practice: a guide for social science students and researcher*, Sage Publications: London
- Lerner, M.J. (1980). *The Belief in a Just World*. Plenum: New York
- Levine, S. (1987). The changing terrains in medical sociology: Emergent concern with quality of life. *Journal of Health and Social Behavior*, 28: 1-6
- Little, M., Paul, K., Jordens, C.F.C. & Sayers, E.J. (2002). Survivorship and discourses of identity, *Psychooncology*, 11: 170-178
- Lohan, M. (2000). Extending feminist methodologies: Researching masculinities and technologies, In A. Bryne & R. Lentin (Eds) *(Re)searching women*, pp. 167-187, IPA:Dublin
- Lowy, A. & Bernhard, J. (2004). Quantitative assessment of changes in patients' constructs of quality of life: An application of multilevel models. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation*, 13(7): 1177-1185
- Macmillan cancer support (2014). *Living with and beyond cancer*, retrieved from <http://www.macmillan.org.uk/Aboutus/Healthandsocialcareprofessionals/Macmillansprogrammeandservices/Survivorship.aspx> [accessed October 2015]
- Manderson, L., Bennett, E. & Andajani-Sutjahjo, S. (2006). The social dynamics of the interview: Age, class, gender, *Qualitative Health Research*, 16: 1317-1334
- Marshall, M.N. (1996). Sampling for qualitative research, *Family Practice*, 13(6): 522-525
- Martin, R.C., Eid, S., Scoggins, C.R. & McMasters, K.M. (2007). Health-related quality of life: return to baseline after major and minor liver resection, *Surgery*, 142(5):676-84
- Mathieson, C.M. & Stam, H.J. (1995). Renegotiating identity: cancer narratives, *Sociology of Health and Illness*, 17 (3), 283-306
- McCahill, L.E., Hamel-Bissell, B.P. (2009). The patient lived experience for surgical treatment of colorectal liver metastases: a phenomenological study, *Palliative & supportive care*, 7(1):65-73
- McClain, C.S., Rosenfeld, B. & Breitbart, W. (2003). Effect of spiritual well-being on end-of-life despair in terminally ill cancer patients, *Lancet*, 361(9369): 1603-1607
- McCoubrie, R.C. & Davies, A.N. (2006). Is there a correlation between spirituality and anxiety and depression in patients with advanced cancer? *Support Care Cancer*, 14(4): 379-385
- McKee, L. & O'Brien, M. (1983). Interviewing men: Taking gender seriously. In E. Gamarnikov, D. Morgan, J. Purvis & D. Taylorson (Eds) *The public and the private*, Heinemann: London

- Mead, G.H. (1934). *Mind, self, and society, from the standpoint of a social behaviourist*, University of Chicago: Chicago
- Mitchell, A.J., Ferguson, D.W., Gill, J., Paul, J. & Symonds, P. (2013). Depression and anxiety in long-term cancer survivors compared with spouses and health controls: a systematic review and meta-analysis, *Lancet*, 14(8): 721-732
- Moons, P., Budts, W. & De Geest, S. (2006). Critique on the conceptualisation of quality of life: A review and evaluation of different conceptual approaches, *International Journal of Nursing Studies*, 43, 891-901
- Morris, B.A., Shakespeare-Finch, J. & Scott, J.L. (2011). Posttraumatic growth after cancer: the importance of health-related benefits and newfound compassion for others, *Support Cancer Care*, 20(4): 749-756
- Moss, T.P. (2005). The relationship between objective and subjective ratings of disfigurement severity and psychological adjustment, *Body Image*, 2, 151-159
- Mullan, F. (1985). Seasons of survival: reflections of a physician with cancer, *New England Journal of Medicine*, 313: 170-173
- NHS Choices (2014) Bowel cancer – Diagnosis <http://www.nhs.uk/Conditions/Cancer-of-the-colon-rectum-or-bowel/Pages/Diagnosis.aspx> [accessed 27/05/15]
- Nordlinger, B., Guiquet, M., Vallient, J.C., Ballardur, P., Bachellier, P. & Jaeck, D. (1996) Surgical resection of colorectal carcinoma metastases to the liver. A prognostic scoring system to improve case selection, based on 1568 patients, *Cancer*, 77(7): 1254-62
- O'Mahony, S., Blank, A.E., Zallman, L., Selwyn, P.A. (2005). The benefits of a hospital-based inpatient palliative care consultation service: Preliminary outcome data, *Journal of Palliative Medicine*, 8(5): 1033-1039
- Ong, J., Clarke, A., White, P., Johnson, M., Withey, S. & Butler, P.E. (2007). Does severity predict distress? The relationship between subjective and objective measures of appearance and psychological adjustment during treatment for facial lipoatrophy, *Body Image*, 4, 239-248
- Park, C.L., Edmondson, D., Fenster, J.R. & Blank, T.O. (2008). Meaning making and psychological adjustment following cancer: The mediating roles of growth, life meaning, and restored just-world beliefs, *Journal of Consulting and Clinical Psychology*, 76(5): 863-875
- Patel, S.S., Floyd, A., Doorly, M.G., Ortega, A.E., Ault, G.T. Kaiser, A.M. & Senagore, A.J. (2012). Current controversies in the management of colon cancer, *Current Problems in Surgery*, 49(7): 398-460
- Puchalski, C., Ferrell, B., Virani, R., Otis-Green, S., Baird, P., Bull, J., Chochinov, H., Handzo, G., Nelson-Becker, H., Prince-Paul, M., Pugliese, K. & Sulmasy, D. (2009). Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference, *Journal of Palliative Medicine*, 12(10): 885-904
- Rauch, P., Miny, J., Conroy, T., Neyton, L. & Guillemin, F. (2004). Quality of life among disease-free survivors of rectal cancer, *Journal of Clinical Oncology*, 22(2): 354-360

- Rees, J. R., Blazeby, J.M., Brookes, S.T., John, T., Welsh, F.K. & Rees, M. (2014). Patient-reported outcomes in long-term survivors of metastatic colorectal cancer needing liver resection, *British Journal of Surgery*, 101: 1468-1474
- Rees, J., Blazeby, J.M., Fayers, P., Friend, E., Welsh, F.K., John, T.G., et al. (2012). Patient reported outcomes after hepatic resection of colorectal cancer metastases, *Journal of Clinical Oncology*, 30(12): 1364-1370
- Rees, M., Tekkis, P.P., Welsh, F.K., O'Rourke, T. & John, T.G. (2008). Evaluation of long-term survival after hepatic resection for metastatic colorectal cancer: a multifactorial model of 929 patient, *Annals of Surgery*, 247(1): 125-35
- Rippentrop, E.A., Altmaier, E.M. & Burns, C.P (2006). The relationship of religiosity and spirituality to quality of life among cancer patients, *Journal of Clinical Psychology in Medical Settings*, 13(1):29–35
- Rozmovits, L. & Ziebland, S. (2004). Patients with colorectal cancer expressed a loss of adulthood related to a loss of professional and sexual identity, dignity, privacy, independence, and ability to socialise, *Qualitative Health Research*, 14: 187-203
- Rubin, H.J. & Rubin, I. (2005). *Qualitative interviewing: the art of hearing data*, Sage Publications: Michigan
- Salz, T., Baxi, S.S., Blinder, V.S., Elkin, E.B., Kemeny, M.M., McCabe, M.S., Moskowitz, C.S., Onstad, E.E., Saltz, L.B., Temple, L.K.F. & Oeffinger, K.C. (2014). Colorectal cancer survivors' needs and preferences for survivorship information, *Journal of Oncology Practice*, 10(4): 277-282
- Sapp, A.L., Trentham-Dietz, A., Newcomb, P.A., Hampton, J.M., Moinpour, C.M. & Remington P.L. (2003). Social networks and quality of life among female long-term colorectal cancer survivors, *Cancer*, 98(8): 1749-1758
- Scheele, J., Stang, R., Altendorf-Hofmann, A. & Paul, M. (1995). Resection of colorectal liver metastases, *World Journal of Surgery*, 19(1): 59-71
- Scheier, M. F, Matthews, K. A., Owens, J. F., Magovern, G. J., Sr., Lefebvre, R. C, Abbott, R. A., & Carver, C. S. (1989). Dispositional optimism and recovery from coronary artery bypass surgery: The beneficial effects on physical and psychological well-being, *Journal of Personality and Social Psychology*, 57: 1024-1040
- Seegerstrom, S.C. (2003). Individual differences, immunity, and cancer: Lessons from personality psychology, *Brain, Behaviour, and Immunity*, 17(1): 92-97
- Seegerstrom, S.C. (2004). Optimism and immunity: do positive thoughts always lead to positive effects? *Brain, Behaviour and Immunity*, 19(3): 195-200
- Seegerstrom, S.C., Taylor, S.E., Kemeny, M.E. & Fahey, J.L. (1998). Optimism is associated with mood, coping, and immune change in response to stress, *Journal of Personality and Social Psychology*, 74(6): 1646-1655
- Sideris, L., Zenasni, F., Vernerey, D., Dauchy, S., Lasser, P., Pignon, J.P., Elias, D., Palma, M. & Pocard, M. (2005). Quality of life of patients operated on for low rectal cancer: impact of the type of surgery and patients' characteristics, *Diseases of the Colon and Rectum*, 48(12): 2180-2191

- Silver, R., Boon, C. & Stones, M.H. (1983). Searching for meaning in misfortune: Making sense of incest, *Social Issues*, 39(2): 81-101
- Simko, L.C. (1999). Adults with congenital heart disease: utilizing quality of life and Husted's nursing theory as a conceptual framework, *Critical Care Nursing Quarterly*, 22(3): 1-11
- Smith, M.Y., Redd, W.H., Peyser, C. & Vogl, D. (1999). Post-traumatic stress disorder in cancer: a review. *Psychooncology*, 8: 521-537
- Snape, D. & Spencer, L. (2003). The foundations of qualitative researcher, in J. Ritchie and J. Lewis, (Eds), *Qualitative Research Practice, A guide for social science students and researchers*, Sage Publications Ltd: London
- Spiegelhalter, D.J., Gore, S.M., Fitzpatrick, R., Fletcher, A.E., Jones, D.R. & Cox, D.R. (1992). Quality of life in health care. III: resource allocation, *British Medical Journal*, 305: 1205-1209
- Sprangers, M.A. & Schwartz, C.E. (1999). Integrating response shift into health-related quality of life research: a theoretical model. *Social Science and Medicine*, 48(11): 1507-1515
- Stanton, A. L., & Snider, P. R. (1993). Coping with a breast cancer diagnosis: A prospective study, *Health Psychology*, 12: 16-23
- Stationary Office (2000). *The NHS plan: A plan for investment, a plan for reform*, London: Stationary office.
- Sumalla, E.C., Ochoa, C. & Blanco, I. (2009). Posttraumatic growth in cancer: Reality or illusion? *Clinical Psychology Review*, 29: 24-33
- Taylor, E.J. (1995). Whys and wherefores: adult patient perspectives of the meaning of cancer, *Seminars in Oncology Nursing*, 11(1): 32-40
- Taylor, E.J. (2000). Transformation of tragedy among women surviving breast cancer, *Oncology Nursing Forum*, 27:781-788
- Taylor, E.J. (2003). Nurses caring for the spirit: Patients with cancer and family caregiver expectations, *Oncology Nursing Forum*, 30(4):585-590
- Taylor, S. E. (1983). Adjustment to threatening events. A theory of cognitive adaptation. *American Psychologist*, 38: 1161-1173
- Taylor, S.E. & Brown, J.D. (1988). Illusion and well-being: A social psychological perspective on mental health. *Psychological Bulletin*, 103: 193-210
- Taylor, S.E., Lichtman, R.R. & Wood, J.V. (1984). Attributions, beliefs about control, and adjustment to breast cancer, *Journal of Personality and Social Psychology*, 46, 489-502
- Tedeschi, R. G., Park, C. L. & Calhoun, L. G. (1998). *Posttraumatic growth: Positive changes in the aftermath of crisis*. Lawrence Erlbaum: Mahwah, NJ
- Tempelaar, R., de Haes, J.C.J.M., de Ruiter, J.H., Bakker, D., van den Heuvel, W.J.A. & van Nieuwenhuijzen, M.G. (1989). The social experiences of cancer patients under treatment: A comparative study, *Social Science and Medicine*, 29(5): 635-642

- The National Cancer Intelligence Network. *Colorectal Cancer Survival by Stage - NCIN Data Briefing*. 2009 [cited 2015 27/05/2015]; Available from: [http://www.ncin.org.uk/publications/data\\_briefings/colorectal\\_cancer\\_survival\\_by\\_stage.aspx](http://www.ncin.org.uk/publications/data_briefings/colorectal_cancer_survival_by_stage.aspx).
- Theofilou, P. (2013). Quality of Life: Definition and measurement, *Europe's Journal of Psychology*, 9(1): 150-162
- Thoits, P. A. (1991). On merging identity theory and stress research, *Social Psychology Quarterly*, 54: 101-112
- Thornton, A.A. & Perez, M.A. (2006). Posttraumatic growth in prostate cancer survivors and their partners, *Psychooncology*, 15:285–296.
- Tomich, P.L. & Helgeson, V.S. (2002). Five years later: A cross-sectional comparison of breast cancer survivors with healthy women, *Psychooncology*, 11: 154-169.
- Tracey, S.J. (2010). Qualitative quality: Eight “Big-Tent” criteria for excellent qualitative research, *Qualitative enquiry*, 16(10): 837-851
- Weisman, A.D. & Worden, J.W. (1976). The existential plight in cancer: significance of the first 100 days, *International Journal of Psychiatry Medicine*, 7(1): 1–15
- WHO. Constitution of the World Health Organization (2003). <http://www.who.int/about/definition/en/print.html>
- Wiering, B., Oyen, W.J., Adang, E.M., van der Sijp, J.R., Roumen, R.M., de Jong, K.P., Ruers, T.J. & Krabbe, P.F. (2011). Long-term global quality of life in patients treated for colorectal liver metastases, *British Journal of Surgery*, 98(4): 565-71
- Williams, A. (1988). *The measurement and valuations of improvements in health*, Newsletter, University of York, Centre for Health Economics, 3
- Williams, A., (1987). The importance of quality of life in policy decision, in Walker, S. and Rosser, E. (Eds), *Quality of Life: Assessment and Application*, MTP Press: Lancaster
- Williams, C.L. & Heikes, E.J. (1993). The importance of researcher's gender in the in-depth interview: Evidence from two case studies of male Nurses, *Gender and Society*, 7(2): 280-291
- Wilmoth, M.C. (2006). Life after cancer: What does sexuality have to do with it? *Oncology Nursing Forum*, 33:905-910
- Winchester, H. (1996). Ethical issues in interviewing as a research method in human geography, *Australian Geographer*, 2: 117-131
- Wyatt, G., Kurtz, M.E. & Liken, M. (1993). Breast cancer survivors: An exploration of quality of life issues, *Cancer Nursing*, 16: 440–448
- Zebrack, B.J. (2000). Cancer survivor identity and quality of life, *Cancer Practice*, 8(5): 238–242
- Zoellner, T., & Maercker, A. (2006). Posttraumatic growth in clinical psychology. A critical review and introduction of a two component model, *Clinical Psychology Review*, 26: 626–653

## Appendix 1: EORTC Questionnaires

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### EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials:

    |\_|\_|\_|\_|

Your birthdate (Day, Month, Year):

    |\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|

Today's date (Day, Month, Year):

31

    |\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a <u>long</u> walk?	1	2	3	4
3. Do you have any trouble taking a <u>short</u> walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

#### During the past week:

	Not at All	A Little	Quite a Bit	Very Much
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4
16. Have you been constipated?	1	2	3	4

Please go on to the next page

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**During the past week:**

	Not at All	A Little	Quite a Bit	Very Much
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your <u>family</u> life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your <u>social</u> activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

**For the following questions please circle the number between 1 and 7 that best applies to you**

29. How would you rate your overall health during the past week?

1      2      3      4      5      6      7

Very poor

Excellent

30. How would you rate your overall quality of life during the past week?

1      2      3      4      5      6      7

Very poor

Excellent

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## EORTC QLQ – LMC21

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

<b>During the past week :</b>	<b>Not at All</b>	<b>A Little</b>	<b>Quite a Bit</b>	<b>Very Much</b>
31. Have you had trouble with eating?	1	2	3	4
32. Have you felt full up too quickly after beginning to eat?	1	2	3	4
33. Have you worried about losing weight?	1	2	3	4
34. Have you had problems with your sense of taste?	1	2	3	4
35. Have you had a dry mouth?	1	2	3	4
36. Have you had a sore mouth or tongue?	1	2	3	4
37. Have you been less active than you would like to be?	1	2	3	4
38. Have you had tingling hands or feet?	1	2	3	4
39. Have you had pain in your stomach area?	1	2	3	4
40. Have you had discomfort in your stomach area?	1	2	3	4
41. Have your skin or eyes been yellow (jaundiced)?	1	2	3	4
42. Have you had pain in your back?	1	2	3	4
43. Have you felt slowed down?	1	2	3	4
44. Have you felt lacking in energy?	1	2	3	4
45. Have you had trouble having social contact with friends?	1	2	3	4
46. Have you had trouble talking about your feelings to your family or friends?	1	2	3	4
47. Have you felt stressed?	1	2	3	4
48. Have you felt less able to enjoy yourself?	1	2	3	4
49. Have you worried about your health in the future?	1	2	3	4
50. Were you worried about your family in the future?	1	2	3	4
<b>During the past four weeks:</b>				
51. Has the disease or treatment affected your sex life (for the worse)?	1	2	3	4

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## Appendix 2: Recruitment table

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## Details of individuals invited to participate in the study

	Gender	Age	Interviewed
1	Male	57	No
2	Male	67	Yes
3	Male	70	Yes
4	Female	77	No
5	Male	72	Yes
6	Male	84	Yes
7	Male	68	Yes
8	Female	78	Yes
9	Male	85	Yes
10	Female	75	Yes
11	Female	69	Yes
12	Male	66	Yes
13	Male	66	Yes
14	Male	73	No
15	Male	78	No
16	Female	78	Yes
17	Female	60	No
18	Male	66	Yes
19	Female	65	Yes
20	Male	70	No
21	Male	67	Yes
22	Female	64	No
23	Male	77	No
24	Female	84	No
25	Male	70	No
26	Female	52	No

## Appendix 3: Interview schedule

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**Section 1: Introduction and icebreaker**

**First of all, could you start by introducing yourself?**

*It is now more than five years since your liver surgery have you had any more treatment or just had follow up and scans or blood tests.*

**How were you first diagnosed?**

**What happened after your diagnosis?**

-Treatment

-Surgical intervention

**When did you find out about the colon cancer you had spreading to your liver? What happened after that?**

**How do you experience compare to what you expected at the start?**

**How do follow-up appointments affect you?**

PROMPTS – emotional impact, practical impact

**Section 2: Quality of life**

*The next area I would like to talk about is quality of life. In broad terms, what we mean by quality of life is wellbeing, and this could be physical, mental or social, but it is not limited to these things. It is different for everyone so we are most interested in what it means to you.*

**What kind of impact do you think it's had on a practical level?**

PROMPTS- lifestyle changes, work, living, day to day care,

**How have your experiences affected your quality of life in the broader sense?**

PROMPTS-

coping with life ability to work/hobbies and normal activities (Role), coping strategies,

social life - family or social activities,

emotions – tense or worried irritable or depressed,

physical abilities, carrying/walking normal activities e.g. washing dressing, activity /vigour – have

you noticed anything about how active you are, do you ever get troubles with discomfort or pain anywhere, troubles with food

**Has this changed over time? Are different things more important now than they were just over diagnosis? Or one year after?**

**Do you feel your experiences have impacted on your relationship?**

PROMPTS – emotional – stress or worry, care giving, sex life

**When things weren't so good, what helped you to get through it? What made it harder?**

### **Section 3: Survivorship and identity**

*So the next things I'd like to talk about are issues around survivorship and identity, and how having this disease may have affected this.*

**Can you tell me whether you feel back to normal or not? Or even feel like someone who never had cancer or not?**

**Have your experience changed your priorities in life?**

PROMPTS- have they changed, what is important now, why has it changed? positive impact, negative impact

**Do you view yourself differently since you've had cancer? How? Why?**

PROMPTS- do you identify yourself as a survivor? How important is this to you? Do you feel it was just a phase or has become part of who you are?

### **Section 4: Questionnaire data**

*Finally I'd like to look at some the questionnaire data we've gathered over the last five years. As I am sure you know we've been asking people with colorectal cancer and liver mets to fill out the same quality of life questionnaire throughout recovery and up until now. We would be really interested to see what you think of the results – do they reflect your own experiences or are they different, do you think they are measuring the right things etc?*

**-Present results**

*Describe how patients feel after this type of surgery in the long term*

Prompt questions

**How do your experiences and how you feel compare with the results?**

**How about over time?**

*The questionnaires cover a number of areas that can affect cancer patients. This is a summary of the topics in the questionnaire.*

**-Present summary list describing domains and symptoms included in the questionnaires**

**Do you think the questionnaires are missing anything important?**

**Do they cover all the issues you've experienced or should some things be added?**

**Is there anything on there you don't think is relevant?**

*The questionnaire was originally designed to look at short term quality of life, right after treatment.*

**Do you think the questionnaires capture everything that has been important for you throughout your recovery up until now?**

**For example were some things relevant right after surgery but are not now? Or Vice versa?**



# 1. Global health and quality of life

## 2. Functional scales

Physical functioning	Emotional functioning
Role functioning	Cognitive functioning
Social functioning	

## 3. Symptoms

Fatigue	Eating
Nausea and vomiting	Activity/Vigour
Pain	Pain
Dyspnoea (Shortness of breath)	Emotional problems
Insomnia (Sleeping problems)	Weight loss
Appetite loss	Taste
Constipation	Dry mouth
Diarrhoea	Sore mouth/tongue
Financial difficulties	Peripheral neuropathy (Tingling in hands or feet)
Talking about feelings	Jaundice (Change of colour of skin or eyes to yellow)
Sex life	Contact with friends

## Appendix 4: Participant documentation: Invitation letter, information sheet, and consent form

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Mrs MD Finch Jones/Professor Jane Blazeby / Mr Jonathan Rees  
Upper GI Department  
Level 3, Dolphin House  
Bristol Royal Infirmary  
Upper Maudlin Street  
Bristol  
BS2 8HW

[j.m.blazeby@bristol.ac.uk](mailto:j.m.blazeby@bristol.ac.uk) / [jonathan.rees@bristol.ac.uk](mailto:jonathan.rees@bristol.ac.uk)

0117 9287269 / 0790 9912187

Date

Dear,

**Understanding the long-term impact of liver surgery for colorectal cancer metastases on health related quality of life and patient experience: Interview study**

We are members of the Surgical Research Unit at the University of Bristol and are writing to you to see if you would be interested in taking part in the above research study about quality of life and how people feel in the long term after liver surgery for colon cancer. You were kind enough to indicate that you would be interested in talking to us about your experiences when you returned the questionnaire you filled out some months ago.

We are inviting you to take part in an interview study to find out how you are now and find out if there are any experiences or events that you felt were particularly important in the time since your surgery

Please find enclosed a patient information sheet which explains the purpose of the study, why you have been chosen and what the study involves.

If you choose to take part please return a signed copy of the enclosed reply slip in the stamped addressed envelope provided. On receiving this form, a member of the research team will contact you to confirm your interest in the study and arrange for you to take part.

If you have any concerns or questions about the study, please feel free to contact Mr Jonathan Rees, Miss Katie Whale, Mrs Meg Finch-Jones or Professor Jane Blazeby (details above).

With kind regards

Jonathan Rees MSc, PhD, FRCS (Gen. Surg)

Katie Whale BSc, MSc

Jane Blazeby MSc, MD, FRCS (Gen. Surg)

Mrs Meg Finch-Jones BA, MD



**Understanding the long-term impact of liver surgery for colorectal cancer metastases on health related quality of life and patient experience: Interview study**

<b>Mr Jonathan Rees</b>	<b>Mrs Meg Finch-Jones</b>	<b>Professor Jane Blazeby</b>
<b>Lecturer in Surgery</b>	<b>Consultant Surgeon</b>	<b>Professor and Consultant Surgeon</b>

Date

**You are being invited to take part in a research study. Before you decide whether or not to participate, it is important for you to understand why the research is being carried out and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Then decide whether or not to take part. Thank you for reading this.**

**The study has been funded by University of Bristol Cancer Research Fund**

**What is the purpose of the study?**

This study involves a single face to face interview with a trained researcher. It aims to assess the quality of life of patients with colorectal cancer with spread to the liver in the long term.

It will particularly focus on your experiences as a survivor of cancer and the effects it had on you and your life.

The information you give us a much deeper insight into patient experiences of surviving this type of cancer. It will also help us to measure patients' quality of life and the effects of some treatments in the long term in a different way to questionnaires which are often used to assess how people feel after cancer treatment.

**Why have I been chosen?**

This study is asking people who have had liver surgery for colorectal cancer to tell in some depth how they have felt as a cancer survivor and tell us the things they have experienced.

About 30 people will be interviewed. They will be both men and women; they will have had treatment in different hospitals and will be of different ages.

**Do I have to take part?**

Your participation in the study is voluntary and it is up to you to decide whether or not to take part. If you agree to take part please sign and return the Reply Slip at the back of this information sheet in the prepaid envelope (at no cost to yourself).

You are free to withdraw at any time and without giving a reason. A decision to withdraw at any time or a decision not to take part will not affect the care you receive in any way. If you decide to take part your GP will be informed in writing.

**What will happen to me if I take part?**

It is up to you to decide whether or not to take part a member of the research team will arrange to meet you at your convenience either at home or when you attend hospital for an appointment. We will ask you to sign a consent form at this meeting.

In the meeting we would like to hear your views on your quality of life since your liver surgery for cancer; your experiences as a cancer survivor and the effect it has had on you in the long term. This will take less than one hour and you will have the opportunity to ask the researcher questions. We will ask us you to give permission for us to tape-record the interview.

**What are the possible disadvantages or risks of taking part?**

There are very few risks of taking part in this study. If you agree to take part, a researcher will ask you about your feelings and experiences about you treatment and surviving cancer. Talking about this may cause some anxiety or concerns. The interviewer would be more than happy to talk through these anxieties or concerns at the time.

If you have any concerns after the interview is over please contact the investigators who can discuss these issues and any other queries you might have.

**What are the possible benefits of taking part?**

The main benefit of participating in this study is that you will be able to improve the information provided to patients who are having surgery for colon cancer that has spread to the liver. The study will provide information about how people feel in the long term after surgery with particular information about their long term experiences as a cancer survivor.

**What if something goes wrong?**

This study has few risks of physical or significant psychological harm. If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms will be available to you.

**Will my taking part in this study be kept confidential?**

All information that is collected about you during the course of the research will be kept strictly confidential. Information will be collected, controlled, stored and analysed by the study researchers at the University of Bristol. Access to this information will be restricted to members of the research team and the study statistician. Any information collected about you will have your name and address removed so that you cannot be recognised from it. You will never be identified in any publications. Audio tapes will be converted to typed copies and the tape immediately wiped. The typed copies of the interview will be stored as anonymous copies and will be destroyed after 15 years in line with Data Protection Act regulations.

Your G.P. will be informed that you are taking part in the research.

**What will happen to the results of the research study?**

We will publish relevant results in scientific journals when the study is complete. You will not be identified in any report or publication. You can request a summary of the study from researchers once it is completed.

**Who is organising and funding the research?**

The study is being funded by the University of Bristol Cancer Research Fund. It is being organised by the University of Bristol.

**Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee (REC). This study has been reviewed by the North East Research Ethics Proportionate Review Sub-Committee.

RECs safeguard the rights, safety, dignity and well-being of people participating in research in the National Health Service. They review applications for research and give an opinion about the proposed participant involvement and whether the research is ethical.

**What if I have any concerns?**

If you have any concerns or other questions about this study or the way it has been carried out, you should contact the investigator or your local NHS Trust patient advice and liaison service whose details are shown below:-

Patient Support & Complaints Team  
Marlborough Street  
Bristol BS1 3NU

Telephone 0117 342 3604

Email: [pals@uhbristol.nhs.uk](mailto:pals@uhbristol.nhs.uk)

Or alternatively you can visit our office which is located on Level 2, Queens Building, Bristol Royal Infirmary

Alternatively, you can contact [ICAS](#), the Independent Complaints Advocacy Service. ICAS is available to help you and advise you should you require assistance with your complaint. ICAS can help you by providing free, independent and confidential support. A member of the Patient Support & Complaints Team can provide you with a copy of their information leaflet. Their contact number is - 0845 120 3782

Thank you for considering taking part in this study.

**Contact for further information**

If you require any further information about the study please contact:

Jonathan Rees  
Jonathan.rees@bristol.ac.uk  
Tel 0117 9287269 / 07909912187

Professor Jane M Blazeby, Professor of Surgery & Consultant Surgeon  
j.m.blazeby@bristol.ac.uk  
Tel 0117 9283495

**Understanding the long-term impact of liver surgery for colorectal cancer metastases on  
 health related quality of life and patient experience: Interview study**

**Mr Jonathan Rees**  
 Lecturer in Surgery  
 Bristol Royal Infirmary  
 Bristol

**Mrs Meg Finch-Jones**  
 Consultant Surgeon  
 Bristol Royal Infirmary  
 Bristol

**Professor Jane Blazeby**  
 Professor and Consultant Surgeon  
 Bristol Royal Infirmary  
 Bristol

PATIENT CONSENT FORM Version 1.1 17/07/12

Participant Identification Number for this study: \_\_\_\_\_

Name of researcher:  
 Please initial box

1.	I confirm that I have read and understand the patient information sheet dated..... (Version 1.1 18/07/2012) for the above study and have had the opportunity to ask questions.	<input type="checkbox"/>
2.	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.	<input type="checkbox"/>
3.	I agree to be interviewed and for my consent consultations to be audio-recorded. I understand that all information collected about me during the course of the research will be kept strictly confidential and will have my name and address removed so that I cannot be recognised from it.	<input type="checkbox"/>
4.	I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from University of Bristol, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	<input type="checkbox"/>
5.	I agree to take part in the above study.	<input type="checkbox"/>

\_\_\_\_\_  
 Name of participant

\_\_\_\_\_  
 Date

\_\_\_\_\_  
 Signature

\_\_\_\_\_  
 Researcher

\_\_\_\_\_  
 Date

\_\_\_\_\_  
 Signature

*1 for participant; 1 for researcher*

## Appendix 5: Analysis clusters

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## Analysis clusters table

Excluded clusters/codes are highlighted with reason provided

CLUSTER	CODE	Exclusion reason
Alternative medicine		Related to short-term treatment choices
Bladder issues		
Bowel issues	Colostomy/stoma	
	Travel	
Cancer community		
Change / impact	Emotional changes	
	Empathy and understanding	
	Family	
	Lack of long-term impact	Combined with 'non-event'
	Physical changes	
	Practical changes	
	Seizing the moment	Renamed as 'living in the moment'
	Worry	Renamed as 'uncertainty and worry'
Communication		
Conflicting emotions		
Coping strategies	Acceptance and getting on with it	
	Goal setting	
	Humour	
	Keeping active	
	Keeping positive	
	Knowledge and understanding	
	Living in the moment	
	Looking forward	Renamed 'forward planning'
	Planning for the future	Renamed 'forward planning'
Denial and avoidance		Included in 'conflicting emotions'
Dependency		
Diagnosis		Related to short-term experiences
Family and partner views		Include throughout as experience specific
Feeling grateful and lucky		
Finance		Included in 'taken away'
Follow-up	Closure	Included in 'causes'. Short-term follow-up experiences not included.
Forgetting		Lack of data to support this cluster
Giving back		
Isolation		Included in 'lack of social understanding' and 'lack of support'
Keeping going	Carrying on with normal life	Renamed 'getting on with it'
	Fighting	Renamed 'fight/battle'
	Getting back to normal	Renamed and combined with 'getting on with it' and 'keeping going'

Life priorities		
Loss	'Taken away'	
Medical system		Related to short-term treatment experiences
Mental health	Paranoia	
	Sadness and depression	
Negative emotions	Anger	
	Disappointment	
	Fear	
	Uncertainty and worry	
Not being yourself		Related to short-term emotional experiences during treatment
Pain		Related to short-term symptoms
Partner		Renamed in 'romantic relationships'
Physical health	Fatigue	Renamed and combined 'fatigue and sleep'
	Physical limitations	
	Sleep	Renamed and combined 'fatigue and sleep'
	Symptoms	Related to short-term symptoms
Recovery		Related to short-term experiences
Relationship		Renamed 'romantic relationships'
Religion		Renamed 'religion/faith/spirituality/beliefs'
Support	Community and friends	
	Family	Renamed – 'family support'
	Lack of support	
	Macmillan	
	Partner	
Survivorship		
Treatment	Chemotherapy	Related to treatment experiences (short-term)
	Hospital experiences	Related to treatment experiences (short-term)
	Practical issues	Related to treatment experiences (short-term)
	Side effects – mental	Related to treatment experiences (short-term)
	Side effects – physical	Related to treatment experiences (short-term)
	Surgery	Related to treatment experiences (short-term)
Uncertainty		Combined and renamed 'uncertainty and worry'
Unexplained emotions		Renamed 'conflicting emotions'
View of cancer	Cancer as 'other'	
	Cancer legacy	Renamed 'legacy'
	Cancer patient perception	Renamed 'patient perception'
	Cause of cancer	Renamed 'causes'
	Closure and lack of focus	Combined and renamed 'non-event'
	Fight / battle	
	Lack of social understanding	
	Mortality	
	Non-event	
	Why me	

View of self and identity		Included in 'Intrapersonal and interpersonal'
Violence		Included in 'anger'
Weight and body image		Lack of data to support cluster. Only one quote.
Work and employment		Primarily short-term impact during treatment. Long-term codes included in 'taken away'

## Appendix 6: Quality criteria

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Tracey (2010) Quality criteria as referenced in Tracey, S.J. (2010). Qualitative quality: Eight “Big Tent” criteria for excellent qualitative research, *Qualitative Inquiry*, 16(10): 837-851

**Table 1.** Eight “Big-Tent” Criteria for Excellent Qualitative Research

Criteria for quality (end goal)	Various means, practices, and methods through which to achieve
Worthy topic	The topic of the research is <ul style="list-style-type: none"> <li>• Relevant</li> <li>• Timely</li> <li>• Significant</li> <li>• Interesting</li> </ul>
Rich rigor	The study uses sufficient, abundant, appropriate, and complex <ul style="list-style-type: none"> <li>• Theoretical constructs</li> <li>• Data and time in the field</li> <li>• Sample(s)</li> <li>• Context(s)</li> <li>• Data collection and analysis processes</li> </ul>
Sincerity	The study is characterized by <ul style="list-style-type: none"> <li>• Self-reflexivity about subjective values, biases, and inclinations of the researcher(s)</li> <li>• Transparency about the methods and challenges</li> </ul>
Credibility	The research is marked by <ul style="list-style-type: none"> <li>• Thick description, concrete detail, explication of tacit (nontextual) knowledge, and showing rather than telling</li> <li>• Triangulation or crystallization</li> <li>• Multivocality</li> <li>• Member reflections</li> </ul>
Resonance	The research influences, affects, or moves particular readers or a variety of audiences through <ul style="list-style-type: none"> <li>• Aesthetic, evocative representation</li> <li>• Naturalistic generalizations</li> <li>• Transferable findings</li> </ul>
Significant contribution	The research provides a significant contribution <ul style="list-style-type: none"> <li>• Conceptually/theoretically</li> <li>• Practically</li> <li>• Morally</li> <li>• Methodologically</li> <li>• Heuristically</li> </ul>
Ethical	The research considers <ul style="list-style-type: none"> <li>• Procedural ethics (such as human subjects)</li> <li>• Situational and culturally specific ethics</li> <li>• Relational ethics</li> <li>• Exiting ethics (leaving the scene and sharing the research)</li> </ul>
Meaningful coherence	The study <ul style="list-style-type: none"> <li>• Achieves what it purports to be about</li> <li>• Uses methods and procedures that fit its stated goals</li> <li>• Meaningfully interconnects literature, research questions/foci, findings, and interpretations with each other</li> </ul>

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## Appendix 7: Systematic review

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## **Abstract**

A systematic review was conducted to identify whether rheumatoid arthritis has a negative impact on body image. Seven studies were identified from the following computerised databases; AMED, ASSIA, CINAHL, MEDLINE, PsycInfo, PubMed, and Web of Knowledge. Findings relating to the impact of rheumatoid arthritis on body image were inconsistent, however a relationship between age of onset and body image was found, with earlier onset being associated with greater body dissatisfaction. Further research is needed to explore this relationship and the impact of rheumatoid arthritis among different age groups. Due to the current heterogeneity of body image measures being used, most of which do not address its multidimensional nature, future studies should adopt broader definitions of body image and also consider the development of rheumatoid arthritis specific body image measures to increase sensitivity.

## **Introduction**

Rheumatoid arthritis (RA) is a chronic inflammatory autoimmune disease which causes swollen, painful joints and is characterised by fluctuating inflammatory activity (Arnett, Edworthy, Bloch, McShane, Fries, Cooper, Healey, Kaplan, Liang, Luthra, Medsger, Mitchell, Neustadt, Pinals, Schaller, Sharp, Wilder, & Hunder, 1988). The inflammatory process can result in pain, joint stiffness, elevated levels of fatigue, and changes in gait and movement (Ryan, 1996). In the UK alone there are over 290,000 existing cases of RA (Wiles, Symmons, Harrison, Barrett, Barrett, Scott & Silman, 1999), with approximately 0.5-1.5% of the population being affected in industrialised countries (Silman & Pearson 2002) and women being three times more likely to be affected than men. Although the pathology and clinical signs and symptoms of arthritis are well documented in the literature, very little attention has been given to the psychological impact of RA. Chronic diseases, especially those accompanied by deformity and disability, can have a significant impact on psychosocial well being, with past research indicating that individuals with RA suffer more psychologically than individuals with other disorders or healthy controls (Ben-Tovim & Walker, 1995).

Previous research has indicated that RA has a significant impact on personal relationships, sexuality, and self image (Gutweniger, Kopp, Mur & Gunter, 1999; Hill, Bird, & Thorpe, 2003). In addition, research carried out with women diagnosed with RA has suggested that they are more likely to develop body disturbances than the general population and have poorer body image. In broad terms, body image refers to how an individual thinks, feels, and behaves in relation to their body and appearance. It is a multidimensional construct and consists of perceptual, cognitive,

affective, and behavioural elements (Weirtheim & Paxton, 2011). There are many definitions of body image, however for the purpose of this review body image will be defined as; the mental image we hold of our bodies, including how we see our size, shape, weight, features, movement and performance, how we feel about these attributes and how these feelings direct our behaviours (Rudd & Lennon, 2000, p.153). This definition has been chosen as it not only provides a multidimensional picture of body image, but also includes the impact of how the body functions in terms of movement and performance, which is extremely pertinent for individuals with RA. Body image can be both positive and negative. Positive body image is related to a positive perception of one's physical appearance and functionality in spite of any perceived imperfections. This can include feelings of acceptance and viewing the body as a favourable influence in one's life. Negative body image relates to negative perceptions of one's physical appearance and dissatisfaction with body performance (Lewis-Smith, Whale & Diedrichs, 2012).

Body image is also strongly influenced by societal expectations of what constitutes a 'normal body'. Western ideals which are prolifically portrayed in the media represent women as having slim, physically fit bodies with low body fat and full functionality, perfect body symmetry and long glossy hair, and represent men as being extremely muscular (Frith, Shaw, & Cheng, 2005; Thompson, Heinbery, Altabe, & Tantleff-Dunn, 2004). When individuals do not match up to these standards it can create negative thoughts and feelings towards oneself and one's body, resulting in negative body image. Due to the focus on having control over one's body, be it in relation to weight and shape or functionality, people with RA may be at particular risk.

For RA patients whose condition can cause joint deformity, impaired mobility, and medical side effects such as weight gain and hair loss (Plach, Stevens & Moss, 2004), body image may be a particularly pertinent issue. The clinical impact of the condition on their bodies coupled with unrealistic societal expectations about what their body should look like and how it should behave, means that individuals with RA could be at much greater risk of developing negative body image compared to a healthy population. Over the disease duration, RA patients must make important decisions about pharmacological treatment, surgical intervention, or occupational therapy adaptations such as orthopaedics or wrists braces. If these patients are experiencing negative thoughts and feelings towards their body resulting from external pressures, it is possible that their decision making process may be guided psychological motivations to 'fit in' with current societal standards, rather than medical reasons such as the prevention of bone erosion or further joint damage. For example, research by Goodacre and Candy (2011) into the acceptability of prescriptive footwear, found that many women were guided by aesthetic rather than clinical and functional reasons. Despite the significant clinical implications of this, there is currently a lack of



research investigating the link between RA and body image, and there has been no attempt to synthesise existing evidence in order to gain a full picture of the impact of the condition. Therefore the purpose of this review is to synthesis existing evidence relating to RA and body image in order to address the following research question; does rheumatoid arthritis negatively affect body image?

## **Method**

A systematic review was conducted according to recommendations from the Cochrane Collaboration and PRISMA guidelines (Cochrane Collaboration Handbook for Systematic Review of Interventions, March 2011; PRISMA Group, 2009). The following computerised databases were searched: AMED (Allied Contemporary Medicine, 1985-11<sup>th</sup> May 2012), ASSIA (Applied Social Science Index and Abstracts, 1987-11<sup>th</sup> May 2012), CINAHL (Cumulative Index of Nursing and Allied Health Literature, 1937-6<sup>th</sup> July 2012), MEDLINE OVID (1966- 30<sup>th</sup> March 2012), MEDLINE EBSCO (1966-20<sup>th</sup> April 2012), PsycInfo (1806-20<sup>th</sup> April 2012), PubMed (1950-11<sup>th</sup> May 2012), Web of Knowledge (1970-6<sup>th</sup> June 2012). Text word, thesaurus and MESH terms were used to maximise the identification of relevant articles. The following keywords were searched using Boolean logic: (1) Body image, physical appearance, weight loss, weight gain, asymmetry, swelling, cosmetic appearance, esthetics, aesthetics, body-self unity, body-self harmony, self-image, body anxiety, self-attitudes, body related self-perceptions, body dissatisfaction, body satisfaction, body esteem; (2) rheumatoid arthritis, juvenile rheumatoid, arthritis, rheumatoid, idiopathic arthritis. Reference lists of relevant articles were also hand searched, and experts in this field of research were contacted for any unpublished research.

### *Inclusion and exclusion criteria*

The inclusion criteria for included articles were (1) published in English; (2) individual with a diagnosis of RA; (3) measure of body image or qualitative theme related to body image; (4) direct association made between diagnosis of RA and body image; (5) included quantitative, qualitative methodology or both.

The exclusion criteria were: (1) literature review or case study article; (2) friend or relative with RA; (3) studies reporting findings not directly relevant to the core concepts of body image, appearance or self-image; (4) no direct association made between RA and body image.

### *Review procedure*

All titles were firstly reviewed according to PICO guidelines (Booth & Fry-Smith, 2004) with all irrelevant articles being excluded (e.g. medical articles or research with animals). Abstracts of remaining articles were then reviewed using the set inclusion and exclusion criteria and full articles were obtained where appropriate. A summary sheet was developed to extract data from the final articles. This included (1) Study details; (2) aims; (3) study design; (4) inclusion and exclusion criteria; (5) recruitment procedure; (6) participant characteristics; (7) disease characteristics; (8) body image measure used; (9) other outcome measures; (10) results. Final articles were also independently assessed by a second reviewer for both content and quality.

Quality assessment was carried out for all final articles to assess risk of bias. Due to the mix of methodological approaches used in the articles, separate quality measures were used for each design. Qualitative and cohort studies were assessed using the CASP guidelines (Critical Appraisal Skills Programme, 2010). As there is currently no specific quality measure for cross-sectional studies, a quality assessment tool was adapted from Wong, Cheung & Hart (2008), Crombie (1996), and Law, Stewart, Pollock, Letts, Bosch and Westmorland (1998).

#### *Data analysis*

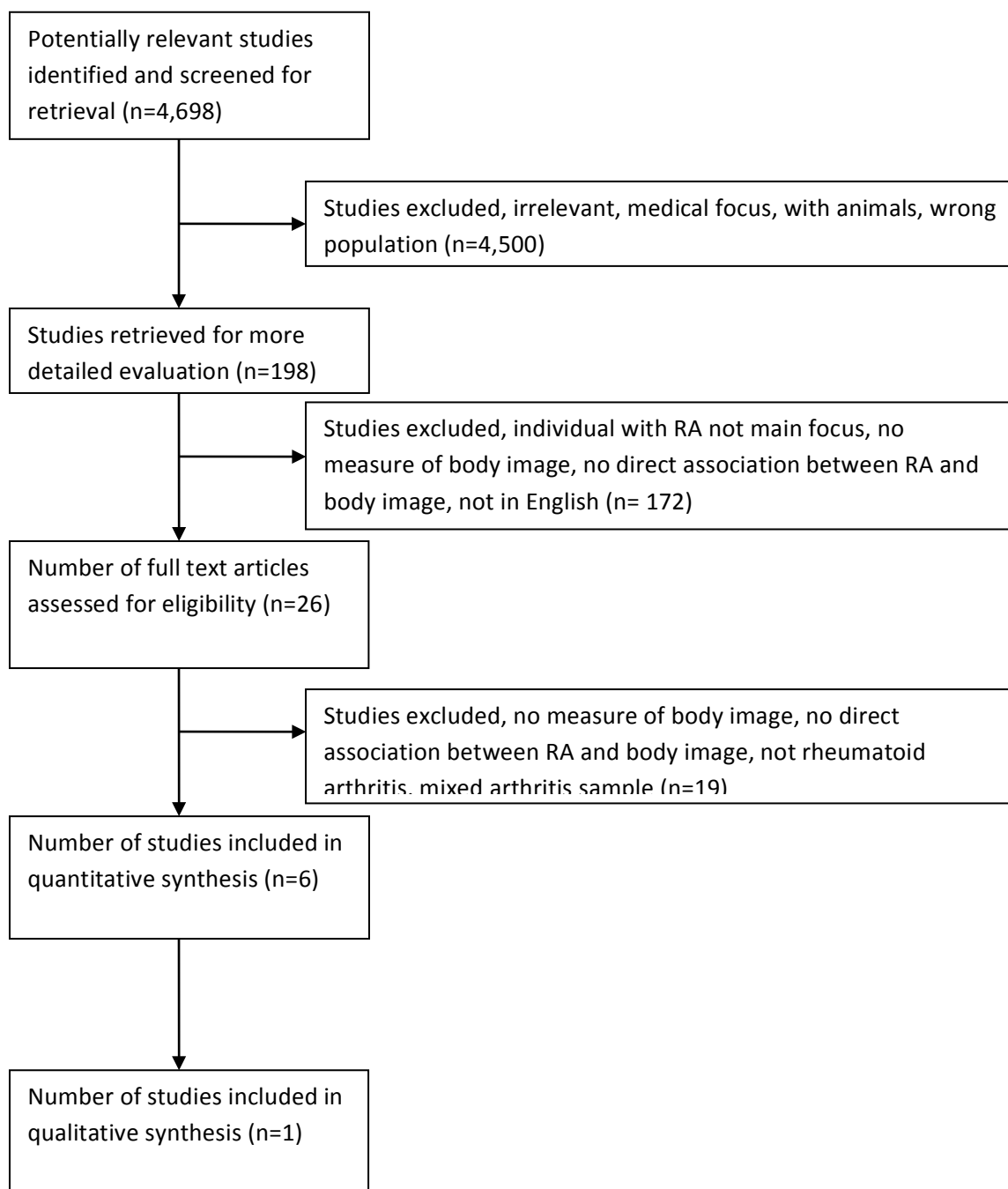
Due to the small number of studies and the mix of methodological approaches, narrative synthesis was considered the most appropriate. During this process qualitative and quantitative evidence were first analysed separately. Cross-sectional and cohort studies focused on the correlation between RA and body image. Qualitative evidence focusing on women's experiences of having a body with RA was tabulated for important information including themes, subcategories and meanings. After this stage the two kinds of data were synthesised together (Goldsmith, Bankhead & Austoker, 2007).

## **Results**

#### *Literature search*

The database searches yielded 4,680 results, with 9 records identified through other sources. From this 198 articles were identified and abstracts obtained. Based on the inclusion and exclusion criteria, 7 articles were selected for review (See Figure 1).

Figure 1: Flow diagram of study retrieval process



### *Research design*

Overall, five studies were cross-sectional, one was a cohort study and 1 was a qualitative study. All body image measures were self report. All studies, except one (Keltikangas-Jarvin, 1987), provided details on RA diagnosis with all participants having a clinical diagnosis of RA, and with two studies citing The American College of Rheumatology criteria and The American Rheumatism Association Criteria (Trajano, Jorge, Brumini, Jones & Natour, 2010; Cornwell & Schmitt, 1990). Five studies included a comparison group of healthy controls (Keltikangas-Jarvinen, 1987; Cornwell & Schmitt, 1990; Ben-Tovim & Walker, 1995; Erkolahti & Ilonen, 2005; Trajano, Jorge, Brumini, Jones & Natour, 2010).

### *Measurement of body image*

Each study used a different measure to assess body image. The measures used were the Offer Self-Image Questionnaire (Offer, Ostrov & Howard, 1982); Body Cathexis Scale (Secord & Jourard, 1953); Draw-a-person test (Koppitz, 1968); Ben-Tovim-Walker Body Attitudes Questionnaire (Ben-Tovim & Walker, 1991); The Body Dysmorphic Disorder Examination (Jorge, Sabino, Natour, Veiga, Jones, & Ferreira, 2008); question six of the Disease Repercussion profile (Carr & Thompson, 1994). The qualitative study asked open ended questions about the impact of RA, participants' perceptions of well-being, and the actions that participants took to control the illness.

### *Demographic characteristics*

Two studies focused on females only (Ben-Tovim & Walker, 1995; Plach, Stevens & Moss, 2004), two had over 70% women (Monaghan, Sharpe, Denton, Levy, Schrieber & Sensky, 2007; Trajano, Jorge, Brumini, Jones & Natour, 2010), one had a relatively even mix of females and males (Erkolahti & Ilonen, 2005), and two gave no information about gender demographics (Cornwell & Schmitt, 1990; Keltikangas-Jarvin, 1987). All studies, except one (Erkolahti & Ilonen, 2005), focused on adults ranging from 18-86 years.

### *Disease characteristics*

All studies, except one (Keltikangas-Jarvin, 1987), included participants with a clinical diagnosis of RA. All participants had been diagnosed with RA for at least six months, with one including patients diagnosed for at least two years (Monaghan, Sharpe, Denton, Levy, Schrieber & Sensky, 2007), and four studies including participants who had been diagnosed for at least ten years (Erkolahti & Ilonen, 2005; Monaghan, Sharpe, Denton, Levy, Schrieber & Sensky, 2007; Plach, Stevens & Moss, 2004; Trajano, Jorge, Brumini, Jones & Natour, 2010). Full study details are summarised in Table 1.

### *Quantitative results*

Overall there were six quantitative studies. Five studies made body image comparisons between RA individuals and controls (Keltikangas-Jarvinen, 1987; Cornwell & Schmitt, 1990; Ben-Tovim & Walker, 1995; Erkolahti & Ilonen, 2005; Trajano, Jorge, Brumini, Jones & Natour, 2010). Three studies found significant differences between the groups, reporting that body image in the RA group was significantly worse than the controls (Keltikangas-Jarvinen, 1987; Ben-Tovim & Walker, 1995; Trajano, Jorge, Brumini, Jones & Natour, 2010). In addition, age of onset was significantly correlated with body disparagement in one study (Ben-Tovim & Walker, 1995) with a younger age of onset being related to greater body disparagement and poorer body image. One study found that the RA group had lower body image than the control group, but the differences were not significant (Erkolahti & Ilonen, 2005). One study found no significant differences between RA individuals and the control group (Cornwell & Schmitt, 1990). One study did not use a control group (Monaghan, Sharpe, Denton, Levy, Schrieber & Sensky, 2007), but found that approximately a third of RA individual felt unattractive or were concerned with their physical appearance.

Ben-Tovim and Walker (1995) conducted a cross-sectional study investigating body attitudes of women with long standing conditions affecting body surface or body functioning. The study included 35 women diagnosed with RA and 14 women diagnosed with Juvenile RA, with both groups being diagnosed on both clinical and serological grounds and having suffered from the illness for at least 12 months. Average age of the RA group was 49.25 years and the average age of the JRA group was 30.86 years. Body image was measured using the Ben-Tovim-Walker Body Attitudes Questionnaire (Ben-Tovim & Walker, 1991). The study found that although the RA group felt less fat than the control group, they felt less attractive to the opposite sex. However these differences were not significant. The JRA group were found to be intensely disparaging about their own bodies and also felt significantly fatter than BMI matched controls. Age of onset was found to be significantly correlated with intensity of disparagement with a younger age of onset being correlated with more intense disparagement and increased salience of weight and shape concerns. Therefore, those participants who had been diagnosed in early adolescence were found to not only have significantly poorer body image than the control group, but also significantly poorer body image than participants who were diagnosed later in life. Although this study did use a control group, there was a lack of detail on the sampling method or any justification for sample size. In addition, due the purposive sample strategy and the risk of selection bias, this participant group is not representative of the RA population as whole and therefore results cannot be generalised.

Cornwell and Schmitt (1990) conducted a cross-sectional study investigating three main questions; (1) the relationship of illness to perceived health status, self-esteem and body image; (2) the relationship between perceived health status and both self-esteem and body image; and (3) the problems, needs and fears of women with RA and systemic lupus erythematosus (SLE). The study included 26 participants with RA who had been diagnosed with either 'definite' or 'classic' RA using the American Rheumatism Association criteria (Ropes, Bennett, Cobb, Jacox & Jessar, 1958), for at least one year. Average age of participants was 50.5 years with a range of 24-79 years. Body image was measured using the Body Cathexis Scale (Secord & Jourard, 1953). The study found that there were no significant differences between the RA and control group on the body image measure, however, there was a significant negative correlation between perceived health status and self-esteem with low perceived health status being related to lower self-esteem. Despite using a control group there was no matching on demographic variables and therefore the study was unable to control for any confounding factors. In addition, a convenience sample was used in both the RA and control groups, with the control group being selected from female alumnae of the University of Rochester, NY. This study is therefore highly at risk of selection bias and, due to the homogeneity of the control group, findings cannot be generalised.

Erkolahti and Ilonen (2005) conducted a cross-sectional study to determine whether there were any differences in the school achievement of adolescents with RA and diabetes mellitus type-1. The study included 24 RA patients with 11 boys and 13 girls who had a clinical diagnosis of medium functional capacity with 8 participants in remission. The mean age of participants was 17.9 years with a mean age of onset of 12.6 years. Body image was measured using the Offer Self Image Questionnaire (Offer, Ostrov & Howard, 1982). The RA group was found to have lower body image than the healthy control group, however the differences were not statistically significant. The control group in this study was matched for sex, age, social background and living environment, thereby controlling for confounding factors, however the RA group was recruited using purposive convenience sample and therefore was at risk of selection bias. In addition, the questionnaire used to assess body image only contains one component relating to body image solely covering positive and negative thoughts about the body. In addition, the measure is only moderately valid and clinically relevant for use in the clinical assessment of adolescents, and consequently may not provide an accurate picture of body image concerns.

Keltikangas-Jarvin (1987) conducted a cohort study to investigate body image disturbances ensuing from JRA. Overall, 68 5-10 year olds were recruited with 28 being diagnosed with JRA (15 5-7 year olds and 13 8-10 year olds), and 41 being diagnosed with temporary arthritis lasting from between 2-6 weeks. The 41 participants with temporary arthritis were used as the control group.

Body image was assessed using the Draw-a-Person test (Koppitz, 1968). At the first test point there were no differences between the two groups, however after one year the frequency of body image disturbance was equivalent in the 8-10 year olds but significantly higher compared to control in the 5-8 year olds. Therefore, young children with JRA are predisposed to develop greater body image disturbances than the control group. Very little information was provided about the study method or recruitment. It is not clear how the study was conducted or if there were any drop outs and how this was handled. In addition, no information was given concerning the validity and reliability of the Draw-a-Person test, or whether a second psychologist provided inter-rater reliability. Although a control group was used it consisted on individuals who had suffered from temporary arthritis and therefore did have some experience of living with an arthritic condition. Therefore this does not provide an accurate picture of body image in individuals with RA compared to those who have never suffered from arthritis. Due to these issues the overall quality of this study is very low and therefore results must be interpreted with caution.

Monaghan, Sharpe, Denton, Levy, Schrieber and Sensky (2007) conducted a cross-sectional study to examine the relationship between physical appearance concerns and psychological distress in patients with rheumatic disease. The study included 53 participants with recent onset RA and 44 participants with chronic RA, but no control group. Both groups had been diagnosed by a consultant rheumatologist with recent onset RA participants being diagnosed with either 'definite' or 'classic' RA by a consultant rheumatologist and also being seropositive for rheumatoid factor. Mean time since diagnosis was 15.5 years. Over 70% of the sample were women with the average age of recent onset participants being 55.06 years and chronic RA 58.63 years. Overall 30% of chronic RA patients reported feeling unattractive and 34% of recent onset patients being concerned with their physical appearance. Appearance concerns were found to be significantly related to depression independent of disability level. In addition, as level of disability was similar in both groups, objective disfigurement was not the sole cause of body image and appearance dissatisfaction.

Trajano, Jorge, Brumini, Jones and Natour (2010) conducted a cross-sectional study investigating body image in patients with RA and the correlation between body image, self-esteem, physical function and quality of life. The study included 43 RA participants who had an established diagnosis of RA based on criteria from the American College of Rheumatology, and were function class I, II or III. Mean disease duration was 12.2 years. Over 83.7% of the sample were women with a mean age of 51.6 years. Body image was measured using the Body Dysmorphic Disorder Examination (Jorge, Sabino, Natour, Veiga, Jones & Ferreira, 2008). The RA group was found to have worse body image than the control group, with worse functionality being related to poorer

body image, even though most participants were in functional group I. There was no direct relationship between disease duration or body image or self-esteem. No matching was used between the control and RA groups to control for confounding factors, with both being recruited through convenience sampling. In addition, the use of the Body Dysmorphic Disorder Examination questionnaire to assess body image raises some significant concerns. This questionnaire was developed for use in clinical settings, often with eating disorder patients. Its primary focus is on the excessive importance given to self-assessed appearance, discomfort in public situations, and withdrawal from social activities. Although these are very important constructs, they do not address many of the key components of body image and therefore fail to provide an accurate picture of body image concerns. The justification given for this is that currently there is no existing measure of body image specific to RA patients. While this is true, there are many alternative body image measures that would have been more appropriate (e.g. The Body Appreciation Scale, Avalos, Tylka, & Wood-Barcalow, 2005; Body Image State Scale, Cash, Fleming, Alindogan, Steadman, & Whitehead, 2002; Appearance Schemas Inventory, Cash, Melnyk, & Hrabosky, 2004) and should have been considered.

#### *Qualitative results*

One study used a qualitative approach. Plach, Stevens and Moss (2004) used qualitative content analysis to describe women's experiences of living with rheumatoid arthritis. This study focused on three main research questions; (1) what is the impact of RA on women's daily lives; (2) what are their perceptions of well being; and (3) what actions do they take to contend with the illness. The study included 30 women with a mean age of 61 years and an age range of 39-86 years. Five of the women had been diagnosed within the past 6-10 years and eleven had been diagnosed for over 10 years. Three main themes were identified; (1) relating to a noncompliant body; (2) body out of sync; and (3) private body made public. Overall women felt that living with RA meant having to relate over time to an increasingly noncompliant body. As function and strength declined over the years, women felt that their body would not respond to their needs making simple tasks such as washing or brushing their hair extremely difficult and sometimes painful. They felt that their bodies would not behave with pain and frustration replacing pleasure. Women also found that their expectations of what their bodies should be like did not fit with reality. They felt out of sync with their age group and with their own expectations of who had they been and who they would become. Finally, women found their inability to keep their condition private very distressing. Where previously they had been able to adapt clothing choices to hide their condition, as the disease progressed and disease deformities or movement restrictions became more severe, people started to notice. Participants reported finding this very humiliating, particularly in relation to their hands. Overall women reported feelings of loathing and shock



when looking at their bodies. In some cases medication had also affected their appearance with participants feeling ugly and bloated, or experiencing hair loss due to drug treatment.

### *Does rheumatoid arthritis negatively affect body image?*

The seven studies included in this review present a mixed set of results regarding the relationship between RA and body image. Three studies found that rheumatoid arthritis had a significantly negative impact on body image with RA patients having worse body image than controls (Keltikangas-Jarvinen, 1987; Ben-Tovim & Walker, 1995; Trajano, Jorge, Brumini, Jones & Natour, 2010). Two other studies also reported that rheumatoid arthritis had a negative impact on body image (Erkolahti & Ilonen, 2005; Monaghan, Sharpe, Denton, Levy, Schrieber & Sensky, 2007). However, results from Erkolhati & Illonen (2005) did not reach statistical significant and the study by Monaghan et al. (2007) did not used a control group and therefore no conclusion can be drawn as to whether these body image concerns are worse than in participants without RA. The qualitative study conducted by Plach, Stevens and Moss (2004) gives some further insight into body image perception of RA patients, however only focuses on those perceptions held by women. This study shows that two of the key issues women with RA experience in terms of body image are functionality and body expectations. Not being able to perform activities which non RA individuals find easy was extremely frustrating for these women and led them to feel disparaged with their bodies. In addition, their bodies did not meet with societal or personal expectations regarding how they should perform on a functional level or what they should look like. This led them to feel out of sync with their bodies and their age group. Furthermore the impact of medication on weight and hair loss also had a negative impact on their body image, with women seeing themselves as ugly and bloated. However, as only one qualitative study was included in this review using a small number of solely female participants these results must be interpreted with caution.

Results show that age of disease onset had a significant impact on body image. Two studies showed that individuals diagnosed at a younger age, either as children or young adolescence, not only had poorer body image than controls but also had poorer body image than individuals who had been diagnosed with RA as adults (Ben-Tovim & Walker, 1995; Keltikangas-Jarvin, 1987). The possible explanations for this will be discussed in further detail in the discussion. One study presented contradictory evidence that RA had no impact on body image compared to a control group. Cornwell and Schmitt's (1990) study with adult women found no statistical differences in body image scored between RA participants and a healthy control group recruited from university alumnae.

## Discussion

Synthesis of both quantitative and qualitative study showed mixed results regarding the impact of RA on body image. One reason for the mix of results may be that past research has failed to address the core of body image concerns due to assumptions being made about what these concerns are. As previously discussed, body image is a multidimensional construct encompassing perceptual, cognitive, affective and behavioural constructs (Weirtheim & Paxton, 2011). It may be that RA has an impact of all of these constructs or just one, but thus far no work has been done to explore this. Therefore, as all the studies included in this review only focused on one aspect of body image, primarily the attitudinal component, it may be that they are failing to measure what is really important to individuals with RA. The medical setting or focus for conducting past research means that most studies have assumed that concerns relating to body image focus purely on appearance and clinically measurable issues, with little attention being given to the psychological components. Qualitative work has highlighted the importance of functionality and body expectations in body image, however none of the measures used in this review have included this. Overall, it appears that many studies have missed a step in the investigation of the impact of RA on body image by making assumptions about what concerns need to be investigated, and choosing measures accordingly, rather than asking patients what their concerns may be without any preconceptions regarding their answers.

Age of disease onset was found to have a significant relationship with body image, with earlier disease onset being significantly related to poorer body image. The reason for this may be that while adults have developed their body image over a number of years and have a more stable sense of self, children and adolescents who are diagnosed with RA do not yet have concrete representations of their bodies and are still developing a sense of self and body image. Therefore, as their body image is arguably at a more malleable stage, their experiences of RA may have a greater impact on their body image leading to a greater risk of developing negative body image. Previous research has shown that due to the body changes that occur during puberty, adolescence is one of the most difficult life stages in terms of physical adjustment (Lioffi, 2003). The added challenges that come with a diagnosis of RA, such as changes to joint appearance, movement limitations, may further contribute to difficulties adapting to and accepting one's body, especially at a time where being 'normal' and 'blending in' is of paramount importance (Lioffi, 2003).

These results may be of particular relevance to health professionals who work with patients with RA. Currently there is very little or no support for RA patients relating to body image and preventing RA related body image disturbances, and although further research is needed to

explore how and why RA may affect body image, evidence from this review suggests that there is a need for this support. Health professionals such as consultants, nurses, and occupational therapists are ideally situated to not only identify these concerns but also address them, and further research should focus on how this might be achieved.

In addition to the provision of general support, the evidence that younger age of onset is associated with greater body dissatisfaction means that there is an even greater need to provide support to children and adolescents diagnosed with RA. Currently little is known about why these issues may be more pertinent in this age group, however it is important that health professionals dealing with this patient groups and also parents and carers of these individuals are aware of these issues.

#### *Methodological limitations*

The most significant limitations of this review are the heterogeneity of the body image measures used, the sample characteristics and the research methodology. Due to the lack of consistency across the studies, comparison and synthesis of results was very challenging. Each study used a different body image measure to evaluate body image concerns in RA individuals, including subscales from broader measures of quality of life, self-esteem, self-image, or perceived physical appearance. This meant that comparing body image results between studies was not possible and therefore limited cross-study comparison.

In addition, as body image is a multidimensional construct including perceptions, affects, cognitions and behaviours (Weirtheim & Paxton, 2011), it is unrealistic that a single measure is able to assess all these components accurately and in sufficient depth. Most measures used in the studies included in this review only address one component of body image, primarily the attitudinal aspects of body image, and therefore very little attentions has been given to the broader emotional, perceptive and behaviours aspects. In addition, no studies presented any evidence that the body image measure was sensitive to specific body image issues associated with RA, or even that the measures had been validated with an RA population. This may be because very little is known about RA specific body image issues, however any future research wishing to explore the relationship between RA and body image should strive to address this issue.

In terms of study quality and risk of bias, more detail needs to be given concerning the sampling methods and sample characteristics. Very few studies gave a justification for the sample size used, or used a sample that was representative of the RA population. All studies used purposive or convenience sample to access RA patients which could lead to sampling and response bias. In

addition, in the five studies that used a control group only two reported matching the groups using demographic variables or using a case control method. The three remaining studies either gave no information on the control group or used a convenience sample with no information on how differences between the groups were controlled for.

#### *Future studies*

This review highlights the need for further research into the impact of RA on all components of body image. Future studies should not only investigate the attitudinal aspects of body image but also the cognitive, perceptual, behavioural and emotional components. In addition, qualitative work is needed to explore what concerns individuals with RA hold, and how they related to their body image, in order for quantitative work to measure the prevalence of these issues on a larger scale. This review has also brought to attention the need to develop standardised body image measures within this patient group, which not only provide a more sensitive measure specific to this condition but also recognise the multifaceted nature of body image.

Due to the evidence that the impact of RA on body image may vary according to age group, longitudinal research may provide a greater insight into how and why these changes occur, and if they fluctuate over time. In addition, as this area is still very under-researched, qualitative data which uses a flexible and exploratory approach could provide much needed insight into what body image issues may be pertinent in this patient group over and above information that is obtained from standardised self-report measures.

In summary, there is insufficient evidence to show whether RA has a negative impact of body image. However, age of onset has been shown to have a significant relationship with body image and body image disturbances. Future research is needed to investigate this relationship, including both quantitative and qualitative methodologies, with focus being directed at the impact of RA on different age groups.