The impact of colorectal cancer, self-efficacy and social support on work ability and employment status: a longitudinal study

This item was submitted to Loughborough University's Institutional Repository by the/an author.

Additional Information:

- A Doctoral Thesis. Submitted in partial fulfillment of the requirements for the award of Doctor of Philosophy of Loughborough University.

Metadata Record: https://dspace.lboro.ac.uk/2134/5805

Publisher: © Manpreet Bains

Please cite the published version.
This item was submitted to Loughborough's Institutional Repository (https://dspace.lboro.ac.uk/) by the author and is made available under the following Creative Commons Licence conditions.

For the full text of this licence, please go to: http://creativecommons.org/licenses/by-nc-nd/2.5/
The Impact of Colorectal Cancer, Self-Efficacy and Social Support on Work Ability and Employment Status: A Longitudinal Study

by

Manpreet Bains

A Doctoral Thesis
Submitted in partial fulfilment of the requirements for the award of Doctor of Philosophy of Loughborough University

December 09

© Manpreet Bains 2009
For my parents
Abstract

Each year approximately 90,000 new cases of cancer are diagnosed in people of working age in the United Kingdom (UK) (Morrell & Pryce, 2005). The potential impact of cancer and its treatment on working life is substantial, with approximately 40% of all cancer patients taking time off work during treatment and recovery (Short, Vasey & Tunceli, 2005). However, little information is available on employment outcomes for those managing colorectal cancer. Colorectal cancer is a commonly diagnosed cancer with approximately 36,000 people diagnosed each year in the UK. Although research demonstrates promising return to work outcomes for this group, not enough is known about the factors (variables) impacting their return to work intentions, work ability and employment outcomes. The aims of this research were to: examine the return to work intentions, work ability and employment outcomes of colorectal cancer patients over six months; explore the role of self-efficacy and psychosocial well-being, and explore the role of health professionals in providing work-related support and information to patients. Findings from these studies may help to better inform future interventions to support this cancer group.

Fifty participants newly diagnosed with colorectal cancer were recruited from three Acute NHS Trusts (n = 27) across the Midlands and a support group (n = 23) affiliated to a National Cancer Charity. Participants completed questionnaires at three time points: baseline (post surgery or pre-treatment); follow-up time 1 (3 months), and follow-up time 2 (6 months). As well as illness and demographic characteristics, the questionnaires measured job self-efficacy, work ability, cancer self-efficacy, quality of life, fatigue and depression. A sub-sample of participants (n = 10) completed a monthly diary over six months. This captured temporal fluctuations and patterns in cancer management, return to work intentions and work ability and the factors impacting upon these (self-efficacy and social support). Finally, 18 health professionals participated in semi-structured interviews that explored the nature and type of work-related advice currently provided to colorectal cancer patients. Data were analysed using both quantitative (ANOVAs and regression) and qualitative techniques (thematic analysis).
The questionnaire study identified varying levels in self-assessed work ability and psychosocial well-being. Most importantly, positive changes in perceptions of cancer self-efficacy $F (1.02, 61.12) = 14.70, p = 0.0005$, and job self-efficacy $F (2, 94) = 10.85, p = 0.0005$ were detected over time; however, interactions between treatment type and time did not emerge ($p > 0.05$). Factors related to perceived work ability outcomes cross-sectionally included type of occupation ($β = 0.31, t = 2.65, p = 0.0005$) and quality of life ($β = 0.42, t = 2.57, p = 0.01$) at baseline, treatment type ($β = -0.19, t = -1.94, p = 0.05$) at follow-up time 1 and job self-efficacy at follow-up time 1 ($β = 0.57, t = 4.40, p = 0.0005$) and time 2 ($β = 0.50, t = 2.92, p = 0.006$). In contrast, factors related to employment status (i.e. working, not working) were job self-efficacy (OR = 2.20, 95% CI: 1.17 – 4.13) at baseline and occupation (OR = 0.03, 95% CI: 0.00 – 0.86), and perceived work ability (OR = 3.05, 95% CI: 1.00 – 12.80) at follow-up time 2. Along with self-assessed work ability at baseline ($β = 0.67, t = 3.99, p = 0.0005$), receiving chemotherapy alone or a combination of treatments (i.e. other than surgery alone) ($β = -0.24, t = -1.99, p = 0.05$) were the strongest predictors of follow-up work ability (independent of age and occupation). Finally, treatment type (OR = 9.91, 95% CI: 1.57 – 62.50) was also identified as the strongest predictor of employment status approximately six months after diagnosis.

Findings from the diary study suggest that self-efficacy beliefs were important in understanding employment outcomes and return to work intentions. The role of such beliefs was multi-faceted and results infer that several factors seemed to impact return to work intentions and self-efficacy temporally. Treatment, symptoms and decrements in perceived work ability were identified as the most prominent factors that served as barriers preventing resumption of work. Moreover, there was a degree of disparity between return to work intent and work ability. Additionally, the diary study identified variation in work-related advice and guidance provided to colorectal patients. Subsequently, some participants may have been under the impression that they were unable to work, especially during treatment.
Results from the interview study found that health professionals attempted to provide guidance to working-aged patients. However, the nature of such guidance varied due to experience, knowledge and time constraints. Furthermore, participants highlighted a lack of knowledge and an insufficient evidence base were barriers to providing more appropriate guidance. The majority of participants stated that this was an aspect of patient care that falls short and to address the issue a concerted multi-disciplinary effort was required.

In short, the findings indicate that the factors related to work ability, return to work intentions and employment outcomes of colorectal cancer patients varied over time, whereby certain variables took precedence over others at particular time points. Furthermore, the results suggest that self-efficacy beliefs are important; however, it is crucial to point out that self-efficacy is unlikely to operate as a stand-alone factor. Indeed, it is argued that it may be a construct that is considered in future research endeavours alongside pre-existing findings, which would inevitably help towards gaining a more comprehensive account of the factors related to the work outcomes of individuals affected by cancer.

**Key words:** Cancer, colorectal, self-efficacy, work ability, employment outcomes, return to work intentions, psychosocial well-being.
ACKNOWLEDGEMENTS

Without a doubt, the writing of this thesis has been the most testing task that I have undertaken so far. During the past three years I have encountered some of my greatest challenges and overcoming these has therefore been all the more rewarding.

First and foremost, I would like to show my deepest gratitude to Dr. Fehmidah Munir and Dr. Joanna Yarker who have acted as my supervisors. Without their knowledge, support and guidance this thesis would not have been possible.

One of the biggest challenges of this endeavour was to gain the support of health professionals who subsequently provided me with the access to recruit patients to participate in this study. I am indebted to Dr. Douglas Bowley, Dr. Nicholas Armitage, Professor Will Steward, Dr. Anne Thomas, their colleagues and their respective NHS Trusts who welcomed and facilitated this study wholeheartedly. I would like to give a special thanks to Sarah Porter and Diana Wick who tirelessly helped to identify patients that were eligible to take part in the study.

I am eternally grateful to my fellow PhD students with whom I have shared an office with during this time; your advice, understanding and support has been deeply appreciated. I would like to thank Himan Punchihewa for saving my sanity and a great deal of time by sharing his knowledge about the secret ways of Microsoft Word! To Katryna Kalawsky, whose journey has been similar to mine, I wish to thank you for your friendship, support and light-hearted banter over the past three years. I would also like to show my heartfelt gratitude to two of my dearest friends, Paramjeet Mahil and Joanne Price whose company has kept me in touch with the outside world.

I would like to thank my parents and family who have provided me with a haven of comfort, love and support that has motivated me to achieve this goal.

Lastly and most importantly, to all the individuals that participated in this study, I cannot thank you enough for your time and effort.
# Table of Contents

Abstract ....................................................................................................................................... i

ACKNOWLEDGEMENTS ........................................................................................................ iv

Table of Contents ....................................................................................................................... v

List of Tables ............................................................................................................................... viii

List of Figures .............................................................................................................................. x

1. Colorectal Cancer, its Treatment and Psycho-Oncology ......................................................... 1
   1.1. Introduction ....................................................................................................................... 1
   1.2. Overview of Cancer ......................................................................................................... 1
   1.3. What is Cancer? .............................................................................................................. 2
   1.4. Commonly Occurring Cancers: The Key Statistics ....................................................... 2
   1.5. Colorectal Cancer ........................................................................................................... 6
      1.5.1. Risk Factors and Causes of Colorectal Cancer ....................................................... 7
      1.5.2. Colorectal Cancer Diagnosis, Staging and Treatment ............................................ 8
   1.6. Physical Effects and Psychosocial Impacts of Cancer ................................................... 15
      1.6.1. Physical Effects ....................................................................................................... 15
      1.6.2. Psychosocial Impacts ............................................................................................. 17
   1.7. The Role of Social Support, Self-Efficacy and Health Professionals ......................... 21
      1.7.1. Self-Efficacy: Theoretical Background .................................................................. 24
      1.7.2. The Development of Self-Efficacy Beliefs ............................................................. 25
      1.7.3. Self-Efficacy in Health Behaviours ....................................................................... 26
      1.7.4. Cancer and Self-Efficacy ...................................................................................... 27
      1.7.5. Self-Efficacy and Cancer Psychosocial Adjustment ............................................. 29
   1.8. Summary ......................................................................................................................... 30

2. Cancer and Employment: Literature Review ....................................................................... 31
   2.1. Introduction ..................................................................................................................... 31
   2.2. Work Absence: The Impact of Diagnosis and Treatment ........................................... 31
   2.3. Return to Work Following Cancer ................................................................................... 33
      2.3.1. Factors Related to Return to Work ....................................................................... 40
   2.4. Cancer and Work Ability ............................................................................................... 44
      2.4.1. Factors Impacting Work Ability ............................................................................ 53
   2.5. Summary ......................................................................................................................... 60
   2.6. Research Objectives, Aims and Hypotheses .................................................................. 62
3. **Methodology** .................................................................................................................. 69
   3.1. Design .......................................................................................................................... 69
   3.2. Recruitment and Ethical Approval .............................................................................. 69
      3.2.1. Participants ........................................................................................................ 70
   3.3. Power Calculation: Sample Size .................................................................................. 71
   3.4. Measures ...................................................................................................................... 72
      3.4.1. Background Questionnaire .............................................................................. 72
      3.4.2. Cancer and Employment Questionnaire ......................................................... 72
      3.4.3. Qualitative Data: Diary .................................................................................... 77
      3.4.4. Health Professionals’ Interview Study ............................................................. 77
   3.5. Procedure ..................................................................................................................... 77
      3.5.1. Questionnaire Administration ......................................................................... 78
      3.5.2. Ethical Considerations ..................................................................................... 80
   3.6. Data Analysis ............................................................................................................... 80

4. **The Impact of Colorectal Cancer on Psychosocial Well-Being and Work Ability** .......................................................................................................................... 82
   4.1. Introduction .................................................................................................................. 82
   4.2. Statistical Analysis ...................................................................................................... 83
   4.3. Results .......................................................................................................................... 83
      4.3.1. The Effect of Time and Treatment upon Psychosocial Well-Being ............... 85
      4.3.2. The Effect of Time and Treatment upon Work Ability .................................... 91
   4.4. Discussion .................................................................................................................... 93
   4.5. Summary ..................................................................................................................... 95

5. **Predictors of Work Ability and Employment Status: The Role of Self-Efficacy** .......................................................................................................................... 96
   5.1. Introduction .................................................................................................................. 96
   5.2. Statistical Analysis ...................................................................................................... 97
   5.3. Results .......................................................................................................................... 99
      5.3.1. Correlation Analyses ....................................................................................... 99
   5.4. Factors Predicting Job Self-Efficacy ............................................................................ 105
   5.5. Factors Predicting Work Ability ................................................................................ 108
   5.6. Factors Predicting Employment Status ...................................................................... 114
   5.7. Discussion .................................................................................................................... 119
6. Exploring Temporal Patterns in Cancer Management, Return to Work Intentions and Work Ability: A Diary Study ..................................................123
   6.1. Introduction ............................................................................................123
   6.2. Methods ....................................................................................................125
      6.2.1. Participants ..................................................................................125
      6.2.2. Materials ......................................................................................126
      6.2.3. Procedure ....................................................................................130
      6.2.4. Analysis .......................................................................................131
   6.3. Results .................................................................................................132
   6.4. Discussion ............................................................................................170
   6.5. Summary ...............................................................................................178

7. Exploring the Role of Health Professionals: An Interview Study .............180
   7.1. Introduction ............................................................................................180
   7.2. Methods ....................................................................................................181
      7.2.1. Participants ..................................................................................182
      7.2.2. Interview Schedule ........................................................................183
      7.2.3. Procedure ....................................................................................185
      7.2.4. Analysis .......................................................................................185
   7.3. Results ....................................................................................................185
   7.4. Discussion ............................................................................................205
   7.5. Summary ...............................................................................................209

8. Discussion ......................................................................................................210
   8.1. Methodological Considerations .............................................................218
   8.2. Implications of Findings and Future Directions .......................................220
   8.3. Conclusion ............................................................................................222

References ........................................................................................................225
Appendices .......................................................................................................252
# List of Tables

Table 1.1: Incidence of five most common cancers in UK, 2004 (Cancer Research UK, 2006a) ................................................................................................................................. 3

Table 1.2: Approximate frequency and five-year relative survival (%) according to Dukes’ Stage (Cancer Research UK, 2006e). ................................................................. 12

Table 1.3: Treatment according to type of colorectal cancer. .................................. 13

Table 2.1: Summary of return to work / work continuance studies. ......................... 34

Table 2.2: Summary of colorectal cancer return to work / work studies.................... 43

Table 2.3: Summary of Work Ability studies. ............................................................ 47

Table 2.4: Employment status of all Finnish Cancer Patients in 1997 (Taskila-Abrandt et al., 2005). .............................................................................................................. 56

Table 3.1: Scales administered at each time point. .................................................. 73

Table 4.1: Socio-demographic and cancer-related characteristics at baseline .......... 84

Table 4.2: Mean, standard deviation and ANOVA results for repeated measures with ‘treatment type’ as between groups factor and ‘time’ as within factor. ......... 87

Table 4.3: Mean (SD) scores of work ability across three time points with scores as dependent variable in a repeated measures ANOVA, with treatment as a between group factor and time as within factor. ................................. 92

Table 5.1: Mean, standard deviations and correlations among the study variables (baseline). .................................................................................................................. 100

Table 5.2: Mean, standard deviations and correlations among the study variables (follow-up time 1). ................................................................. 102

Table 5.3: Mean, standard deviations and correlations among the study variables (follow-up time 2). ................................................................. 104

Table 5.4: Hierarchical multiple regression analysis of variables associated with job self-efficacy (dependent variable) at baseline (N = 50). ................................. 106

Table 5.5: Hierarchical multiple regression analysis of variables associated with job self-efficacy (dependent variable) at follow-up time 1 (n = 49). .................. 107

Table 5.6: Hierarchical multiple regression analysis of variables associated with job self-efficacy (dependent variable) at follow-up time 2 (n = 49). .............. 108
Table 5.7: Hierarchical multiple regression analysis of variables associated with work ability as the dependent variable at baseline ($N=50$)..............................110

Table 5.8: Hierarchical multiple regression analysis of variables associated with work ability as the dependent variable at follow-up time 1 ($n=49$)..................111

Table 5.9: Hierarchical multiple regression analysis of variables associated with work ability as the dependent variable at follow-up time 2 ($n=49$)...............112

Table 5.10: Longitudinal Hierarchical Regression analysis for work ability at follow-up time 2 ($n=49$). ...........................................................................................................113

Table 5.11: Hierarchical Logistic Regression variables related to employment status at baseline ($N=50$). ...........................................................................................................115

Table 5.12: Hierarchical Logistic Regression variables related to employment status at follow-up time 2 ($n=49$). ...........................................................................................................117

Table 5.13: Longitudinal Hierarchical Logistic Regression variables related to follow-up time 2 employment status ($n=49$). ...........................................................................................................119

Table 6.1: Demographic profiles of participants ($n=10$). ..................................................127

Table 6.2: Themes and sub-themes. ....................................................................................133

Table 6.3: Perceived self-efficacy in ability to self-manage cancer according to time point..........................................................................................................................134

Table 6.4: Perceived self-efficacy in ability to self-manage work according to time point..........................................................................................................................155

Table 7.1: Demographic profiles of participants ($n=18$). ..................................................184

Table 7.2: Themes and sub-themes. ....................................................................................187
List of Figures

Figure 1.1: Five year age standardised relative survival (%), adults diagnosed 1996-1999, England and Wales by sex and site (Cancer Research UK, 2007). ...5

Figure 1.2: Diagram of the large bowel (Cancer Backup, 2007a). ..................................7

Figure 3.1: Diagram of Protocol ....................................................................................79

Figure 4.1: Mean scores over time with fatigue as the dependent variable in a repeated measures ANOVA, with ‘treatment type’ as between group factor and ‘time’ as within factor. Lines represent standard deviation. ........................................86

Figure 4.2: Mean (SD) scores over time with depression scores used as the dependent variable in a repeated measures ANOVA, with ‘treatment type’ as between group factor and ‘time’ as within factor. Lines represent standard deviation. ....................................................................................................................88

Figure 4.3: Mean (SD) scores over time with work quality of life used as the dependent variable in a repeated measures ANOVA, with ‘treatment type’ as between group factor and ‘time’ as within factor. Lines represent standard deviation. ....................................................................................................................89

Figure 4.4: Mean (SD) scores over time with cancer self-efficacy used as the dependent variable in a repeated measures ANOVA, with ‘treatment type’ as between group factor and ‘time’ as within factor. Lines represent standard deviation..........................................................90

Figure 4.5: Mean (SD) scores over time with job self-efficacy used as the dependent variable in a repeated measures ANOVA, with ‘treatment type’ as between group factor and ‘time’ as within factor. Lines represent standard deviation. ....................................................................................................................91

Figure 4.6: Mean (SD) scores over time with work ability used as the dependent variable in a repeated measures ANOVA, with ‘treatment type’ as between group factor and ‘time’ as within factor. Lines represent standard deviation. ....................................................................................................................92

Figure 6.1: Diary study procedure within context of questionnaire study..................129

Figure 6.2: Mean (SD) self-efficacy in ability to self-manage cancer according to time point. ..........................................................................................................................134

Figure 6.3: Mean (SD) job self-efficacy according to time point.................................156
Figure 6.4: Return to work barriers. .................................................................173

Figure 6.5: Summary of relationship between cancer self-efficacy and work self-efficacy and factors impacting upon these. .................................................................177
1. **Colorectal Cancer, its Treatment and Psycho-Oncology**

1.1. **Introduction**

The aim of the following chapter is to provide some background regarding cancer and the associated treatment(s); this is necessary to understand how these factors may impact an individual's work ability and return to work outcomes. Firstly, the chapter will present a brief overview about cancer and the key statistics associated with the disease, particular attention will be paid to commonly diagnosed cancers. Secondly, the chapter will move on to consider colorectal cancer in more detail as this cancer type will form the focus of this thesis. In particular, how it is diagnosed, staged and treated will be discussed. Thirdly, the physical effects of treatment and psychosocial impacts of cancer will be considered as these have been shown to be important in understanding illness management and employment outcomes. At present, little is known about how such factors may impact those affected by colorectal cancer. Finally, the possible role of self-efficacy (perceived self-beliefs in ability to perform a task or behaviour) as a psychosocial factor, that has not previously been considered, especially in relation to understanding work outcomes of cancer patients, will be discussed.

1.2. **Overview of Cancer**

Statistics indicate that approximately a quarter of a million persons are diagnosed with cancer each year in the UK; this approximates to 1 in 3 people (Cancer Research UK, 2006a). In order to understand how cancer affects people, it is important to begin by providing a brief overview about the nature of cancer and to present some of the important statistics associated with the disease. In doing so, prognosis, treatment effects and impacts on quality of life outcomes, including quality of working life, can then be understood.
1.3. What is Cancer?

Cancer is a group of diseases affecting the cells of the body. It arises when the processes governing cell growth and division in the human body become out of control (Cancer Backup, 2007). Normally, as cells grow old and die, new cells are formed to replace them; however, in some cases the cells continue to divide which leads to the formation of a lump that is known as a tumour. Tumours can be benign or malignant where the latter are cancerous; malignant tumours comprise of cells that have the ability to spread to different areas and, if left untreated, these cells can spread to the surrounding tissues and organs via the bloodstream and lymphatic system (Cancer Backup, 2007). If these cells reach a new area they can continue to divide leading to another tumour: this new tumour is known as a secondary cancer or metastasis (Cancer Backup, 2007). As the human body is made up of many types of cells, it is not surprising that there are over 200 different types of cancer each with their own type of diagnosis, treatment and prognosis (Cancer Backup, 2007).

1.4. Commonly Occurring Cancers: The Key Statistics

Statistics from the UK show breast, lung, bowel (colorectal) and prostate cancers account for more than 50% of all new cases (Table 1.1) (Cancer Research UK, 2006a). Commonly diagnosed cancers in men are prostate (23%), lung (16%), colorectal (14%) and bladder cancer (5%) (Cancer Backup, 2007); for women, breast (31%), colorectal (11%), lung (11%) and ovarian cancers (5%) are the most common (Cancer Backup, 2007). Age is a risk factor for most cancers with 64% of cases observed in those aged 65 years and above (Cancer Research UK, 2006a). However, 1 in 10 cancers are diagnosed in those aged between 25 and 50 years (Cancer Research UK, 2008), with women aged between 30 and 50 years at more risk of developing cancer than their male counterparts. Colorectal cancer incidence is highly associated with increasing age (Cancer Research, 2006c; 2006d). Bowel Cancer UK (2006) report that 90% of people diagnosed with colorectal cancer are aged over 55 years (average age of 70 years), although, colorectal cancer diagnoses are also on the increase in younger persons (Bowel Cancer UK, 2006).
Table 1.1: Incidence of five most common cancers in UK, 2004 (Cancer Research UK, 2006a).

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>Male</th>
<th>Female</th>
<th>% of total cancer population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>324</td>
<td>44335</td>
<td>15.69</td>
</tr>
<tr>
<td>Lung</td>
<td>22495</td>
<td>15818</td>
<td>13.46</td>
</tr>
<tr>
<td>Colorectal</td>
<td>19657</td>
<td>16452</td>
<td>12.69</td>
</tr>
<tr>
<td>Prostate</td>
<td>34986</td>
<td>0</td>
<td>12.29</td>
</tr>
<tr>
<td>Bladder</td>
<td>7168</td>
<td>2925</td>
<td>3.55</td>
</tr>
</tbody>
</table>
Despite the increasing prevalence and incidence of cancer, the outlook for those diagnosed with cancer appears to be promising. Due to improvements in detection and treatment cancer survival rates have increased dramatically in the last ten years (Cancer Research UK, 2006a). In particular, for men, the highest five-year survival rates are associated with testicular cancer whereas for women it is malignant melanoma (Figure 1.1) (Cancer Research UK, 2007). When considering commonly diagnosed cancers, the estimated relative five-year survival rate for breast cancer is approximately 80% (Cancer Research UK, 2005a; 2006e; 2007). For colorectal cancer, the five-year relative survival rate has doubled between the 1970s and 1990s (approximately 23% to 50%); however, if diagnosed early these rates are reported to be as high as 83% (Cancer Research UK, 2006e). In contrast, the survival rates for lung cancer are low, with only 25% likely to survive one year after diagnosis (Cancer Research, UK 2007).

The prior discussion sought to provide an insight into cancer in a general sense. However, the focus of this thesis is on colorectal cancer. At present, little information is available on those managing colorectal cancer, particularly in relation to their work outcomes. Each year approximately 36,000 people are diagnosed with colorectal cancer in the UK (Bowel Cancer UK, 2006); this is the second most commonly diagnosed cancer in women and the third most commonly diagnosed in men (Cancer Backup, 2007). Due to improvements in bowel cancer screening, detection, treatment and, therefore, survival, research in this area is important for the following reasons. Firstly, although colorectal cancer is diagnosed with increasing age (90% diagnosed are over 55 years, Bowel Cancer UK, 2006) a proportion of these will be working and due to falling birth rates and people living longer, Government and policymakers are encouraging people to work for longer (Centre for Research in the Older Workforce, 2004). Secondly, as well as undergoing chemotherapy or radiotherapy treatment, surgical treatment may result in life changes (e.g. stoma appliance) which, in turn, may impact colorectal cancer patients’ ability to resume everyday activities such as continuing with or returning to work. Currently, there is very little information for employers and patients on this aspect. Finally, few studies have considered the key psychosocial factors that
may impact upon work ability for colorectal cancer (e.g. self-efficacy, social support and treatment).

Figure 1.1: Five year age standardised relative survival (%), adults diagnosed 1996-1999, England and Wales by sex and site (Cancer Research UK, 2007).

The following discussion will describe this type of cancer, the apparent risk factors and causes, diagnosis (staging) and treatment in more detail. It is necessary to provide this background prior to moving on to the next chapter which will aim to discuss how cancer has been reported to impact ability to work and return to work outcomes.
1.5. Colorectal Cancer

Colorectal cancer (cancer of the large bowel) refers to growths, lumps or tumours that arise in the colon and rectum which make up the large bowel. The bowel wall consists of numerous layers; these cancers start to develop in the innermost layer (bowel lining). If left untreated or undiagnosed the cancer can spread through the layers and eventually pass through the bowel wall (Cancer Research UK, 2002). According to Cancer Research UK (2002), bowel cancer can take between 5 and 10 years to develop, beginning predominantly as polyps / adenomas (bowel wall growths). Statistics indicate that two-thirds of colorectal cancers are diagnosed in the colon and one-third in the rectum (Cancer Backup, 2007a). To understand colorectal cancer, it is appropriate to outline the parts of the body involved and how they function normally. The bowel (see Figure 1.2), is part of the digestive system and is often referred to as the gastrointestinal tract (GI tract). It is split into the small bowel (small intestine) and the large bowel, comprising of the colon and rectum; this is where the majority of bowel cancers are diagnosed; cancer of the small bowel, on the other hand, is rare (Cancer Research UK, 2002). The large bowel (colon) is 5 feet long and surrounds the small bowel which is approximately 20 feet long: the small bowel is narrower than the large bowel, hence the name. The digestive system processes food that has been consumed, converting it into energy and nutrients that the body can utilise (Cancer Research UK, 2002; Cancer Backup, 2007a). This process begins once food has passed down the oesophagus to the stomach. The small bowel then absorbs the essential nutrients from the food. The digested food is then passed through the large bowel where the colon absorbs water from the food and the rectum stores waste matter until it is ready to be passed from the body (Cancer Research UK, 2002; Cancer Backup, 2007). The large bowel consists of five sections (see Figure 1.2). Cancer can arise in any of these areas: 1) the ascending colon – starts at the appendix at the bottom of the small bowel and runs up the right-hand side of the abdomen; 2) the transverse colon – goes across the body; 3) the descending colon – goes down the abdomen to the sigmoid colon; 4) the sigmoid colon – this joins the descending colon to the rectum, and 5) the rectum
– this is the back passage where waste matter is held until it is passed through the anus.

### 1.5.1. Risk Factors and Causes of Colorectal Cancer

The causes of colorectal cancer are still largely unknown (Cancer Backup 2007a), although it has been reported that certain individuals are more at risk of developing colorectal cancer than others. The most prominent risk factor is **age**: 90% of those diagnosed are aged over 55 years (Bowel Cancer UK, 2007). **Prior history** of colorectal cancer also leads to an increased risk (Cancer Research UK, 2002).

An additional risk factor is **family history**: it is estimated that between 5% and 10% of those diagnosed with bowel cancer (in the UK) have a family history of the illness (Bowel Cancer UK, 2007). However, this risk is contingent upon certain conditions: if bowel cancer is diagnosed in a first degree relative under the age of 45 years, or is diagnosed in several members of the same family (Cancer Backup, 2007; Cancer Research UK, 2002; Bowel Cancer UK, 2007).
There are two inherited genetic conditions that increase colorectal cancer risk: Familial Adenomatous Polyposis (FAP) and Hereditary Non-Polyposis Colon Cancer (HNPCC) (Cancer Backup, 2007; Cancer Research UK, 2002; Bowel Cancer UK, 2007). FAP causes benign tumours known as polyps in the large bowel. Over time these polyps can become cancerous particularly by the age of 40 to 50 years (Cancer Research UK, 2002). FAP can arise in those without a family history of the condition. HNPCC is another rare inherited genetic condition where the healthy form of this gene aids DNA repair. Therefore, possessing the faulty gene leads to an increased risk of developing various cancers with the highest risk being associated with developing bowel cancer (Cancer Research UK. 2002). Both FAP and HNPCC account for 1 in 20 bowel cancers (Cancer Research UK, 2002; Cancer Backup, 2007a). Non-inherited risk factors such as benign polyps and / or adenomas (growths in the bowel) can also lead to bowel cancer. In fact, it has been suggested that most bowel cancers develop from these (Cancer Research UK, 2002). Interestingly, 1 in 4 has one or more adenomas by the age of 50 years but only a small number will develop into cancer over a long period of time (Cancer Research UK, 2002).

There is some evidence to suggest that individuals affected by inflammatory bowel diseases such as ulcerative colitis or Crohn’s disease which cause inflammation of the large bowel have an increased risk of developing colorectal cancer (Cancer Backup, 2007a). Additionally, it has been suggested that a diet high in animal fat and proteins and low in fibre may increase the risk of developing colorectal cancer (Cancer Backup, 2007a; Chao et al., 2005). However, there is research to counteract this argument (Park et al., 2005). Likewise, those participating in behaviours such as smoking (American Cancer Society, 2000), consuming large amounts of alcohol (Su & Arab, 2004) and a sedentary lifestyle may be at a higher risk of developing the disease (Cancer Research UK, 2002; Cancer Backup, 2007a).

1.5.2. Colorectal Cancer Diagnosis, Staging and Treatment

For this thesis, it is important to understand how colorectal cancer is diagnosed, staged and treated. This is because the stage of a colorectal cancer is likely to
determine a patient’s treatment pathway which in turn may have implications on prognosis and subsequently impact upon return to work intentions, work ability and employment outcomes. More specifically, staging will determine the extent of the cancer (local / spread / nodal involvement) and the subsequent treatment(s) that will be administered to the patient. Hence, this will allow one to gain an insight into the extent to which these factors may impact upon individuals’ ability to work, their return to work intentions and other employment outcomes.

**Diagnosis and Staging of Colorectal Cancer**

Colorectal cancer can take many years to develop. However, the earlier it is diagnosed the greater the likelihood it can be cured. The symptoms of colorectal cancer are similar to those associated with more common bowel conditions (e.g. Irritable Bowel Syndrome, Inflammatory Bowel Disease). These may include: abnormal bowel habit, blood in stools, weight loss, abdominal pain, fatigue, anaemia, vomiting, constipation and a feeling of bloatedness (Cancer Backup, 2007a). A number of tests can be used to diagnose colorectal cancer including:

1) Proctoscopy – involves inserting a small tube (proctoscope) into the back passage to examine the inside lining of the rectum; 2) Sigmoidoscopy – involves using a camera and light to examine the rectum and colon; 3) Faecal Occult Blood Test – investigates the presence of blood in the stools; 4) Colonoscopy – this lighted probe is inserted into the rectum and allows the whole colon to be looked at. The test involves taking images and biopsies of the cells (Cancer Backup, 2007a); 5) Barium enema – this is an x-ray of the large bowel; 6) Magnetic Resonance Imaging (MRI) scan - this uses magnetic and radio waves to build up images of all the tissues in the body. It is particularly useful in providing an initial indication of the stage of the disease (this staging is carried out by the radiologist and fed back to colorectal consultants to decide how the patient will be treated), and 7) Computerised tomography (CT) colonography – which involves inserting a colonoscope into the bowel where a computer uses CT images to examine the area (Cancer Backup, 2007a; Cancer Research UK, 2008). Additional tests are often used
once cancer has been identified to find out the precise size and location, these include: blood tests; chest x-rays; abdominal ultrasound scan, and CT scans (Cancer Backup, 2007a).

The staging of a cancer indicates the size of the tumour, whether it has spread, the type (and order) of treatment an individual will undergo and helps to determine the prognosis and survival rate (Cancer Research UK, 2002; Cancer Backup, 2007a). This is relevant to the present study as the type and number of treatments an individual undergoes is likely to have far reaching implications for example, on prognosis which in turn will impact the resumption of normal activities including ability to work. Studies have found that the more treatment an individual undergoes the worse the impact on work ability and return to work outcomes (Bradley, Neumark, Luo, & Schenk, 2007; Amir et al., 2007; de Boer et al., 2008). There are two staging systems used to identify the stage of a cancer: The Dukes staging system and the TNM staging system. These staging systems are often used interchangeably and consultants often refer to one or both systems when discussing the stage of a tumour. These are described briefly below:

*The Dukes Staging System*

This staging system was introduced by Dr. Cuthbert E. Dukes (1932), which stages colorectal cancer in the following way:

**Dukes A** – The cancer is only affecting the innermost lining of the colon or rectum.

**Dukes B** – The cancer has spread to the muscle layer of the colon or rectum.

**Dukes C** – The cancer has spread to at least one of the lymph nodes near the bowel.

**Dukes D** – The cancer has spread to another part of the body such as the liver or the lungs (metastases / secondary cancer).
The TNM Staging System

The TNM staging system (Tumour, Node, Metastases) is becoming the commonly adopted method for staging a cancer (Wittekind & Sobin, 2002; Cancer Backup, 2007a; Cancer Research UK, 2002). The staging system identifies the size of the tumour (T), the presence of cancer cells in the lymph nodes (N) and whether the cancer has spread to another part of the body (M). Please refer to Appendix 1 where more detailed information regarding this staging system is provided.

Staging will determine whether the affected individual is treated with curative intent or with a palliative approach. Thus, the more advanced the tumour the poorer the prognosis is. Table 1.2 shows approximate five-year relative survival rates associated with the Dukes’ staging system (Cancer Research UK, 2006e). The table shows the majority (35%) of colorectal cancers are diagnosed at Dukes’ stage B; whereas only 11% are diagnosed at the earliest possible stage (Dukes’ A). When considering this within the context of this study, individuals with Dukes’ A or B colorectal cancers are more likely to recover, have a better prognosis and be able to resume near normal daily activities such as returning to work than individuals affected by Dukes’ C or D cancer. Furthermore, the perceived work ability of those with earlier stage disease is likely to be better and more comparable with pre-cancer levels than those with later staged disease. Treatment, particularly the number of treatment types individuals will undergo is another important factor that is likely to impact perceived work ability and work outcomes in the current study.

Treatment of Colorectal Cancer

The treatment of colorectal cancer is selected according to the stage and location of the cancer in the bowel (Cancer Backup, 2007a). Colon and rectal cancers are often treated using different methods. Different treatments have been reported to have varying affects on quality of life (Gruber et al., 2003; Kennedy, Haslam, Munir & Pryce, 2007), return to work outcomes (Buckwalter et al., 2007; Balak et al., 2008) and work ability (Taskila, Martikainen, Hietanen & Lindbohm, 2007; de Boer et al., 2008; Drolet et al., 2005).
Table 1.2: Approximate frequency and five-year relative survival (%) according to Dukes’ Stage (Cancer Research UK, 2006e).

<table>
<thead>
<tr>
<th>Dukes’ Stage</th>
<th>Approximate frequency at diagnosis (%)</th>
<th>Approximate five-year survival (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>11</td>
<td>83</td>
</tr>
<tr>
<td>B</td>
<td>35</td>
<td>64</td>
</tr>
<tr>
<td>C</td>
<td>26</td>
<td>38</td>
</tr>
<tr>
<td>D</td>
<td>29</td>
<td>3</td>
</tr>
</tbody>
</table>

Specifically, more profound adverse affects are reported in those undergoing more than one treatment modality (Bradley, Oberst & Schenk, 2006). Table 1.3 summarises the different treatments usually given to colorectal patients.

The treatment pathway varies according to colon and rectal cancers, thus, each will be considered separately. For colon cancers, surgery is commonly undertaken to remove the part of the bowel (colon) containing the cancer. The type of surgery is dependent upon the location of the cancer. Procedures include total-colectomy (removal of colon), hemi-colectomy (half of the colon removed), sigmoid-colectomy (sigmoid colon removed), or a transverse colectomy (transverse colon removed). These procedures also remove nearby lymph nodes which are checked to see if the cancer has spread (Cancer Backup, 2007a). Patients are often advised to rest for at least six weeks after surgery (advised not to drive for this amount of time). However, this varies based upon the patient’s characteristics, including the nature of his / her employment. Furthermore, subsequent treatments may also impact an individual’s work outcomes. For those whose cancer is in the early stages (Dukes’ A), surgery alone is usually sufficient; for those with more advanced stage bowel cancer (Dukes’ B or C) chemotherapy is often given to reduce the risk of recurrence, particularly if the cancer has spread to nearby lymph nodes (Cancer Backup, 2007a).
### Table 1.3: Treatment according to type of colorectal cancer.

<table>
<thead>
<tr>
<th>Type of Colorectal Cancer</th>
<th>Surgery</th>
<th>Chemotherapy</th>
<th>Radiotherapy</th>
<th>Monoclonal Antibodies</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Early Stage Colon Cancer</strong></td>
<td>Surgery can often remove the cancer. Those whose cancer is confined to the inner lining of the bowel rarely need other treatment.</td>
<td>Chemotherapy is often given to those whose cancer may have grown into the muscle layer, to prevent recurrence. This is given after surgery. Chemotherapy is often given to those with lymph node involvement (after surgery).</td>
<td></td>
<td>Often given with chemotherapy to destroy the cancer cells.</td>
</tr>
<tr>
<td><strong>Rectal Cancer</strong></td>
<td>Surgery is used to remove the cancer.</td>
<td>Chemotherapy can be combined with radiotherapy (chemoradiotherapy), and administered prior to surgery to shrink the cancer.</td>
<td>Radiotherapy can be given prior to surgery.</td>
<td></td>
</tr>
<tr>
<td><strong>Advanced Colon Cancer</strong></td>
<td>Surgery can remove some of the cancer cells, or secondary cancers.</td>
<td>Chemotherapy is commonly given to control the disease for a length of time. It can also reduce symptoms.</td>
<td></td>
<td>Can be used to control the advanced disease.</td>
</tr>
<tr>
<td><strong>Advanced Rectal Cancer</strong></td>
<td>Surgery can remove some of the cancer cells, or secondary cancers.</td>
<td></td>
<td>Radiotherapy is commonly used to shrink the tumour, which is causing discomfort (palliative radiotherapy).</td>
<td></td>
</tr>
</tbody>
</table>
For those with rectal cancer, surgery is conducted to remove the tumour (where possible). Those with rectal cancers are more likely to be left with a colostomy because of less healthy bowel remaining (Cancer Backup, 2007a). Rectal surgical procedures include: anterior resection (upper rectal tumours) or abdominal-perineal resection (lower rectal tumours). Radiotherapy is often given prior to, or following, surgery. Prior to surgery, five sessions over a week can help to shrink the tumour, allowing it to be removed more easily during surgery. Like chemotherapy, radiotherapy is also given to try and prevent the cancer from recurring (Cancer Backup, 2007a). A larger tumour usually requires a longer course of radiotherapy treatment and is often combined with chemotherapy (chemoradiotherapy) (Cancer Backup, 2007a). Radiotherapy after surgery is administered if cancer cells are still present, or if the cancer has passed into the bowel wall or nearby lymph nodes (Cancer Backup, 2007a).

For those whose colorectal cancer has surpassed to an advanced stage and spread to other areas, for example, the liver or lungs (metastatic disease), cure is not usually attainable (Cancer Backup, 2007a; Cancer Research UK, 2007). Therefore, palliative treatment is provided in an attempt to control the cancer for as long as possible and treatment is given to alleviate symptoms experienced by the patient.

Consequently, for patients undergoing more than one treatment modality, it is likely that the impact on an individual’s normal routine (including work decisions) may be more profound than those undergoing surgery alone. For example, those undergoing chemotherapy and / or radiotherapy may experience treatment side effects such as fatigue, nausea, diarrhoea and reduced resistance to infection. Therefore, the implications of treatment can be far reaching for an individual; for instance, an individual’s work environment may prevent them from returning or continuing with work due to the risk of infection (Cancer Research UK, 2008a). Being left with a colostomy (if bowel cannot be rejoined upper part is brought out onto the abdominal wall) or ileostomy (end of small bowel is brought onto of the abdominal wall) after surgery may also have implications for work outcomes, particularly for those formerly in physically demanding or manual work who may experience problems such as bag
leakages (Cancer Research UK, 2008b). Although the treatment types colorectal patients undergo are similar to other cancer types, the effects are somewhat different; these include altered bowel habits which can take time to return to normal after surgery. At present, the impact of colorectal cancer and the associated treatment effects and outcomes (e.g. colostomy / ileostomy) upon work ability and work outcomes have not been considered. The following section will move on to consider some of the physical effects and psychosocial impacts experienced by persons affected by cancer and its associated treatments.

1.6. Physical Effects and Psychosocial Impacts of Cancer

Numerous studies have examined the physical effects and psychosocial impacts of cancer on quality of life outcomes. Evidence suggests many cancer patients experience nausea, pain, fatigue, depression, poor quality of life, low self-esteem and stigma as a result of their cancer diagnosis, treatment and recovery (Spelten et al., 2003; Short, Vasey & Tunceli, 2005; Pasquini et al., 2006). It is important to understand the extent and nature of these effects as they are likely to have implications on work ability and return to work intentions. For example, those experiencing symptoms of fatigue may perceive that their work ability is poor, which in turn prevents them from being able to return to work, or it may take them longer to return to work compared with someone not experiencing such symptoms (Spelten et al., 2003). Evidence suggests that the more side effects or symptoms experienced can exacerbate detrimental effects on work ability and work outcomes (Spelten, Sprangers & Verbeek, 2002). The most commonly occurring physical side effects and psychosocial impacts are discussed in more detail below.

1.6.1. Physical Effects

This section will consider the most common physical side effects associated with different types of cancer treatment. Where possible, those side effects reported specifically in colorectal cancer patients will be discussed. It is likely that physical effects vary from person to person (Cancer Research UK, 2008a).
One individual may experience more physical effects whilst undergoing treatment than someone else, or to a higher degree.

**Surgery**

For colorectal cancer patients, surgery can lead to post-operative pain which can be treated with pain killers if necessary (Cancer Research UK, 2008c). In addition, patients may experience problems with eating and drinking post-operatively as it takes time for the bowel to resume its normal function (Cancer Research UK, 2008c). Certain foods may affect the lining of the bowel and colostomy function, perhaps indefinitely. For example, foods high in fibre can lead to loose stools, including diarrhoea (Cancer Backup, 2007a). However, no set guidance is provided on this as people react differently to certain foods (Cancer Backup, 2007a). For those with an ileostomy or colostomy, there is the added need to get used to their stoma appliance; this is because it can take several weeks for patients to learn how to fit the bags and many also experience problems with bag leakages (Cancer Backup, 2007a). Subsequently, one could argue that such problems could prevent patients resuming everyday activities. For example, some individuals may be unsure or lack confidence in their ability to manage symptoms such as diarrhoea or changing a colostomy bag whilst at work.

**Chemotherapy**

Whilst chemotherapy treatment seeks to destroy damaged cells, it can also lead to normal cell damage which in turn can result in a number of unpleasant side effects (Cancer Research UK, 2008d; Cancer Backup, 2007a). Hair (loss / thinning), skin and nails are often affected during chemotherapy. Fatigue is also common in those undergoing chemotherapy (Spelten et al., 2003). Evidence suggests fatigue can worsen as treatment progresses and persist after treatment has ceased. Studies have shown fatigue to impact return to work in those diagnosed with cancer (Spelten et al., 2003). Cancer-related fatigue as a psychosocial impact of cancer is discussed in more detail further on (p. 18). Physical effects relating to the digestive system such as nausea and diarrhoea are also reported (Cancer Research UK, 2008d). This can add to the existing bowel problems colorectal patients experience due to their diagnosis.
and surgery (Cancer Backup, 2007a). An increased risk of infection, tiredness and breathlessness is also linked to the diminished ability of bone marrow to produce blood cells. Furthermore, damage to the nerves can produce tingling in the hands and feet and this can take some time to improve (Cancer Backup, 2007a). Chemotherapy-related side-effects such as fatigue, nausea, reduced mental capacity (e.g. lack of concentration) have been shown to impact everyday life, including work ability (e.g. de Boer et al., 2008).

**Radiotherapy**

Radiotherapy treatment aims to destroy cancer cells in the affected area (Cancer Research UK, 2008e). Like chemotherapy, normal cell damage can also occur (Cancer Research UK, 2008e). Tiredness and fatigue can arise and persist for a number of months after treatment because the body continues to repair damage to healthy cells. Radiotherapy is often administered to those diagnosed with rectal cancers, hence, leading to stomach and pelvic area physical effects, such as diarrhoea, spasms in bowel muscles, sickness and vomiting (Cancer Research UK, 2008f). Moreover, radiotherapy to the large bowel can lead to tenesmus, which is a need to go to the toilet often (Cancer Research UK, 2008f). Bladder irritation, including a burning feeling when passing urine, a need to pass urine often, pain and incontinence can all arise after radiation to the stomach and / or pelvic area in rectal patients (Cancer Research UK, 2008g). Unlike chemotherapy, hair is only lost at the radiated area (Cancer Research UK, 2008e).

1.6.2. **Psychosocial Impacts**

A cancer diagnosis can lead to feelings of distress, anxiety, fear and anger (Weisman, 1976; Brothers & Anderson, 2008); some of these symptoms may exacerbate over time (during and after treatment) leading to symptoms of fatigue (Bower et al., 2000; 2006), depression (den Oudsten et al., 2009) and altered quality of life (Arndt et al., 2006). These psychosocial impacts are commonly exhibited in cancer patients, particularly whilst undergoing treatment. The following discussion will therefore focus on these psychosocial factors in more detail.
Fatigue

According to Lawrence et al. (2004), fatigue is the most distressing side effect of cancer treatment and the impact of fatigue has been studied extensively in cancer patients. According to Curt et al. (2000), fatigue is one of the most common and problematic symptoms experienced by cancer patients. Researchers suggest cancer-related fatigue is different to normal fatigue, in that it is more severe, lasts longer and is not relieved by sleep (Poulson, 2001; Jean-Pierre et al., 2007). Research by Cella et al. (2002) emphasises this point as their study found fatigue to be worse in cancer patients compared with the general US population. Subsequently, Mock (2001, p. 1700) describes cancer-related fatigue as, “an unusual, persistent, subjective sense of tiredness related to cancer or cancer treatment that interferes with usual functioning.” Both physiological and psychological factors are considered to contribute to the onset and maintenance of cancer-related fatigue (Kangas et al., 2008); consequently, cancer-related fatigue was accepted as a diagnosis in the International Classification of Diseases 10th Revision Clinical Modification (Portenoy & Itri, 1999). However, definitions of cancer-related fatigue, operationalising diagnosis and assessment are not universally accepted (Kangas et al., 2008) rendering it difficult to compare findings across studies.

The prevalence of fatigue during cancer treatment ranges from 25% to 99% in the literature. Estimates of fatigue experienced in those undergoing either radiotherapy, chemotherapy, hormone therapy and biological therapy commonly fall between 30% and 60% (Lawrence et al., 2004). Some continue to experience fatigue after treatment, for instance, Bower et al. (2000; 2006), reports a third of breast cancer survivors experienced symptoms at 1 to 5 years and 5 to 10 years post diagnosis. Furthermore, 21% reported fatigue symptoms at both assessments (Bower et al., 2006); these estimates are supported in the literature (Cella, Davis, Breitbart & Curt, 2001). The subsequent impact of fatigue on everyday life is also well documented (Curt et al., 2000). Curt et al. (2000) found that 50% of cancer patients reported that fatigue impacted on physical and social well-being, social activity and ability to work.
Depression

Depression is also frequently observed in cancer patients (Sharpley & Christie, 2007) and can interfere with an individual’s ability to sleep, eat and work (Cancer Research UK, 2009). However, unlike fatigue, it is argued to be the least acknowledged (and diagnosed) psychosocial impact of cancer and cancer treatments (Cancer Research UK, 2009a). This is surprising as estimates of its prevalence are of concern with as many as 1 in 2 experiencing depressive symptoms (Cancer Research UK, 2009a). However, prevalence rates of depression vary immensely in the literature, where estimates predominantly fall between 10% and 25% (Massie, 2004; Sellick & Crooks, 1999).

The prevalence of depression varies according to cancer type and treatment type. The cancer types highly associated with depression include oropharyngeal (Davies, Davies & Delpo, 1986; Cavusoglu, 2001), pancreatic (Fras, Litin & Pearson, 1967; Joffe et al., 1986), breast (Sneeuw et al., 1993; Sachs et al., 1995), and lung (Buccheri, 1998; Montazeri et al., 1998). Cancers with a less high prevalence of depression include colon (Fras et al., 1967; Koenig, Levin & Brennan, 1967), gynaecological (Golden et al., 1991) and lymphoma (Devlen, Maguire, Phillips & Crowther, 1987). Few studies have considered mood disturbance in patients with colorectal cancer (Ramsey et al., 2002). Although lower prevalence levels of depression have been reported in those with colon cancer (Fras et al., 1967; Koenig et al., 1967), more recently, Ramsey et al. (2002) report that colorectal cancer patients still exhibit prevalence levels of depression that exceed those seen in the general population.

Regarding treatment, Schagen et al. (1999) found higher levels of depression in women undergoing chemotherapy for breast cancer compared with those who did not receive this treatment. A recent study by Fann et al. (2009) found depressive symptoms were more severe during treatment when compared to prior treatment scores in a mixed cancer sample ($N = 342$). These studies suggest that depression has a strong impact on cancer patients and their quality of life. Subsequently, studies have found depression also affects return to work and work ability outcomes which will be discussed later (Cancer Research UK,
Chapter 1  Colorectal Cancer, its Treatment & Psycho-Oncology

2009). However, more detailed information is needed on how such symptoms may impact those diagnosed with colorectal cancer.

Quality of Life

A number of studies report that cancer and its treatment can lead to poorer levels of quality of life in patients (Arndt et al., 2004; 2006; Tsunoda et al., 2007). Quality of life is defined as, “a multidimensional concept encompassing behavioural competence and health, perceived quality of existence, and psychological well-being” (Robb et al., 2007, p. 85). Quality of life can refer to specific domains of life (social function, physical function, emotional well-being) or to an overall evaluation of life (de Haes & van Knippenberg, 1985) and has become an important outcome measure for cancer patients (Arndt et al., 2004).

Studies suggest that quality of life in cancer patients is significantly lower than levels seen in the general population (Arndt et al., 2004; 2005; Karadjova, Shishkov & Petrov, 2007; Robb et al., 2007; Ding, Zhu & Zhang, 2007). These studies have investigated the quality of life of cancer patients with at least a year of survivorship after diagnosis or surgery (Karadjova et al., 2007; Robb et al., 2007; Arndt et al., 2004; 2005). Compared with the general population, colorectal cancer patients showed similar quality of life scores in global and physical functioning, but significantly lower emotional and social functioning quality of life (Karadjova et al., 2007). Similar results have been found in ovarian cancer patients (Ding et al., 2007) and breast cancer patients (Arndt et al., 2004; 2005; Robb et al., 2007). According to Arndt et al. (2005), such negative impacts on quality of life can persist for three years after diagnosis.

Treatment type may be an important factor impacting upon quality of life outcomes; for example, Tsunoda et al. (2007) investigated quality of life patterns in five domains in colorectal cancer patients each month for a year after surgery. The study found quality of life in five domains (physical function, role function, fatigue, pain, and dyspnoea) was significantly lower at one month post surgery when compared with pre-operative scores (Tsunoda et al., 2007). Subsequent assessments found that scores for these domains returned to pre-operative values within three months of the operation. Overall, seven of the
quality of life scale scores improved within this time (global quality of life, emotional function, social function, insomnia, appetite loss, diarrhoea and financial difficulties). Furthermore, when compared with a non-chemotherapy group, those undergoing adjuvant chemotherapy showed worse scores (over 12 month period) on a number of quality of life domains (e.g. role function, physical function, cognitive function, emotional function, fatigue and appetite loss) (Tsunoda et al., 2007).

Differences in quality of life are also apparent according to the age of the cancer patient / survivor (Karadjova et al., 2007; Arndt et al., 2004; 2005, Robb et al., 2007). Karadjova and colleagues (2007) observed more deficits in younger colorectal patients (<60 years) compared with older ones (Karadjova et al., 2007; Arndt et al., 2004; 2005). Other researchers argue that older patients report worse global quality of life and physical functioning, but have higher levels of emotional functioning than younger patients (Vinokur, Threatt, Caplan & Zimmerman, 1989; Stone, Richards, A’Hern & Hardy, 2000; Tomich & Helgeson, 2002). However, such studies are criticised for comprising of selective samples and individuals with wide survival times (Arndt et al., 2004). Furthermore, it is difficult to compare findings across studies due to the different measures utilised.

Overall, it is evident that cancer and the associated treatment(s) produce a number of physical effects and psychosocial impacts that may continue after the completion of treatment. It is clear that such problems may lead to an inability to function in a manner similar to pre-diagnosis. Problems with diet, digestion (abnormal bowel habits / colostomy), nausea, fatigue and depression could interfere with performing everyday activities including resuming work and work ability.

1.7. The Role of Social Support, Self-Efficacy and Health Professionals

Evidence suggests that psychosocial factors such as fatigue and depression can impact individuals’ quality of life and work outcomes (Spelten et al., 2002; Taskila & Lindbohm, 2007). However, few studies have considered the role of factors such as social support, self-efficacy and health professionals’ advice
and guidance. Some studies have investigated how self-efficacy and social support are important factors in patients' management of their cancer diagnosis and treatment, however, the impact of these two factors on work ability and return to work intentions have scarcely been considered. Further to this, there is a need to understand the role health professionals play in providing information about the management of cancer and work. The nature of the patient and health professional relationship during cancer diagnosis and treatment is important. In terms of cancer management, health professionals provide information to cancer patients on diagnosis, treatment and prognosis. However, little is known about the extent to which health professionals provide work-related advice and guidance. Please refer to Chapter 2 (pp. 67-68) which discusses the potential importance of this factor in more detail. Studying these factors will enable a more comprehensive understanding of how such factors may impact colorectal cancer patients' (cancer patients in general) return to work intentions, work ability and employment outcomes. The next section will consider the potential importance of social support and self-efficacy in turn.

Social Support

Those diagnosed with cancer are reported to experience feelings of vulnerability, loss of control and uncertainty about their future (Helgeson & Cohen, 1996; Sammarco, 2001). Understanding how people adapt to a cancer diagnosis is important as it will help to identify the factors that lead to more positive adjustment (Coughlin, 2008). The presence and utilisation of social support could be one of the factors that facilitate better adjustment (Carver, 2005; Rowland & Baker, 2005). It has been argued that the level of social support an individual receives is likely to influence his / her ability to seek and process cancer-related information, regulate emotions and decision making (Arora et al., 2007). The role of social support has been studied in the cancer population immensely (Michael et al., 2002; Sapp et al., 2003). After a diagnosis individuals often seek out social support from various sources such as family, friends and caregivers. Moreover, individuals may turn to additional sources of support, for example, support groups and cancer information charities (e.g. Cancer Backup UK).
Research on the role of social support has led to mixed findings. The beneficial value of social support is well documented and reported to improve patients’ psychological adjustment to cancer, well-being and survival (Sapp et al., 2003; Michael et al., 2002; Jackson et al., 2007). Studies on breast cancer found social support was associated with better survival outcomes (Funch & Marshall, 1983; Maunsell, Brisson & Deschenes, 1995). In a randomised control trial, Cassileth et al. (1985) found those that received the psychosocial intervention showed significant increments in survival compared with the control group; however, this finding was not observed in those with more advanced stage disease (Cassileth et al., 1985). In 307 (all female) colorectal cancer survivors, Sapp et al. (2003) found a positive association between social network scores and mental health outcomes, however, this association was not observed in physical health outcomes. Alternatively, in a study that comprised of 699 women diagnosed with breast cancer (on average four years post diagnosis), Michael et al. (2002) found that the presence of social support enhanced physical functioning and that social integration improved health-related quality of life. The study also found socially isolated women reported more problems, hence, were more negatively affected by the cancer. However, a limitation of this study and many other studies (including cancer and employment literature) is that samples comprise of participants diagnosed at various time points. It is likely that the role and nature of social support alters over time, whereby, at diagnosis the role of health professionals (e.g. nurse specialists) may be more important than support from family, friends and employers. Alternatively, social support from employers would be more important when an individual is considering a return to work.

Much of the research discussed suggests that social support could improve patients’ health outcomes and overall quality of life (Coughlin, 2008; Michael et al., 2002; Jackson et al., 2007). As social support is something that is modifiable, the promise for interventions incorporating this appears to be encouraging. In addition to considering social support from family / friends, the current research aims to examine the role of social support in the workplace and how this may impact subsequent employment outcomes.
The Role of Self-Efficacy

Self-efficacy is the perceived confidence an individual has in their ability to perform a task or behaviour (Marks, Allegrante & Lorig, 2005); self-efficacy has been studied immensely in relation to various health behaviours in applied settings. However, little is known about how self-efficacy may impact the illness management and work outcomes, particularly the perceived work ability of colorectal cancer patients. Research suggests that being employed can have positive psychosocial impacts such as improving self-esteem and quality of life (Barofsky, 1989). From such findings it could be argued that cancer patients’ self-efficacy beliefs may influence the psychosocial impact of cancer. The proceeding discussion will consider the application of self-efficacy to health behaviours and cancer. Firstly, self-efficacy theory will be outlined and the development of these beliefs will be discussed. Secondly, the application of the theory will be considered in relation to chronic disease self-management. This will indicate the usefulness of the theory in various applied settings. Finally, the discussion will focus on how self-efficacy has been studied in relation to cancer.

1.7.1. Self-Efficacy: Theoretical Background

The self-efficacy construct was incorporated as a feature of the Social Cognitive Theory (Bandura, 1977; 1986). According to Bandura (1977), existing learning theories including his own (social learning theory) were missing a key feature: self-efficacy (self-beliefs). The social cognitive theory takes the view that cognitive, vicarious, self-regulatory and self-reflective processes are crucial in human adaptation and change (Bandura, 1986). Human functioning is therefore governed by behavioural, cognitive and other personal factors and environmental factors which form a triadic model (Bandura, 1986; Pajares, 2002).

Self-efficacy beliefs are argued to be the most central types of thoughts influencing an individual’s actions (Bandura, 1986). Self-efficacy is, “concerned with how people judge their capabilities and how their self-percepts of efficacy affect their motivation and behaviour” (Bandura, 1986, p. 391). According to Bandura (1997), these perceived beliefs play a major role in how individuals
think, feel, motivate themselves and act in a variety of situations. Individuals differ in terms of the beliefs they hold. Some individuals will believe that they are capable of executing the necessary actions to attain a particular goal; others may believe that they are less capable and as a result may choose to avoid a situation altogether.

The usefulness of self-efficacy has been demonstrated empirically, whereby, self-efficacy beliefs were found to contribute significantly to human motivation and attainment (Bandura, 1992). Such findings lend support to Bandura’s suggestion that self-efficacy beliefs impact individuals’ lives in a global sense. Pajares (2002) encapsulates this argument effectively in that efficacy beliefs influence “whether they think productively, self-debilitatingly, pessimistically or optimistically; how well they motivate themselves and persevere in the face of adversities; their vulnerability to stress and depression and the life choices they make” (Pajares, 2002, p. 4).

1.7.2. The Development of Self-Efficacy Beliefs

According to Bandura (1997), self-efficacy beliefs can be shaped by four sources of influence. Firstly, there are mastery experiences, whereby, previous endeavours are most influential (Pajares, 2002). Not surprisingly, prior successes would enhance an individual’s sense of self-efficacy and failures would weaken it (Bandura, 1997). Therefore, self-efficacy beliefs are dynamic as they continue to adapt as various cognitive, behavioural and self-regulatory tools are attained over the life-course (Bandura, 1997). Secondly, vicarious experiences of observing others influence the creation and strengthening of efficacy beliefs. However, these exert a weaker influence upon self-efficacy beliefs than mastery experiences (Pajares, 2002). Thirdly, the social persuasion an individual receives from others regarding their capability (can be positive or negative) can impact the development of self-efficacy beliefs (Litt, 1988; Pajares, 2002). Finally, individuals also utilise their physiological and emotional states (anxiety, stress, arousal and mood) when judging their capabilities (Bandura, 1997). Positive mood has been found to enhance perceived self-efficacy (Ewart, 1992); whilst a negative mood weakens it (Kavanagh & Bower, 1985). Consequently, efficacy beliefs could be changed
by reducing stress and negative emotions and correcting the misperceptions individuals have about emotional and physical reactions (Bandura, 1997). It is these sources of efficacy information that are used to evaluate self-efficacy beliefs (Bandura, 1986).

1.7.3. Self-Efficacy in Health Behaviours

The concept of self-efficacy has been incorporated into many models of behaviour (Bandura, 1977). For instance, many public health campaigns are rolled out to promote the adoption of healthy practices (Bandura, 2004); these health communications have been argued to alter health behaviours via four mechanisms (Meyerowitz & Chaiken, 1987). The mechanism most relevant to the present discussion is that altering one’s perceived self-efficacy beliefs can lead to the adoption of healthful practices. In other words, beliefs in their own efficacy to alter habits are enhanced (Bandura, 2004). Thus, according to Bandura (2004), the most useful approach to adopt is to “change the emphasis from trying to scare people into health to enabling them with the self-management skills and self-beliefs needed to take charge of their health habits” (p. 148). Consequently, this is the commonly adopted approach. The pivotal role of self-efficacy will now be discussed in relation to chronic disease self-management and cancer.

Chronic Disease Self-Management

The importance of self-efficacy has been studied in relation to chronic disease management (Clark & Dodge, 1999; Bodenheimer, Lorig, Holman & Grumbach, 2002; Grace et al., 2006; Lorig, Ritter & Jacquez, 2007). Many individuals affected by a chronic condition such as diabetes are responsible for its day-to-day management; this comprises of medical management (medication, adhering to a diet and so on), maintaining, changing and creating behaviours to coincide with the ever-changing condition and by dealing with the psychosocial factors associated with having an illness (Lorig & Holman, 2003). Self-efficacy is argued to have an important mediating role in self-management activities, adopting and maintaining health behaviour changes and health outcomes (Strecher et al., 1986; Bodenheimer et al., 2002; Marks et al., 2005). Reasons
for the effectiveness of self-efficacy based interventions are that these beliefs are modifiable and can impact health status, motivation levels and adherence to prescribed regimens. As a result, intervention approaches focusing on self-efficacy hold much promise for improving chronic disease outcomes (Marks et al., 2005).

Studies have shown that self-management programmes utilising self-efficacy enhancing strategies produce more positive outcomes than standard interventions (Lorig et al., 1985; Barlow, Williams & Wright, 1999). In a self-management program for women with heart disease Clark and Dodge (1999) found self-efficacy significantly predicted disease management behaviours (medication adherence, exercise, managing stress, following a diet) at 4 and 12 months after baseline. Other researchers lend support to the argument that changes in self-efficacy lead to changes in health status (Lorig & Holman, 2003). Moreover, enhancing self-efficacy which leads to better disease self-management has been shown to influence quality of life outcomes favourably (Han, Lee, Lee & Park 2003). Alternatively, health outcomes worsened in those with lower self-efficacy beliefs due to poor self-management (Han et al., 2003). It is possible that self-efficacy plays a vital role in a number of health behaviours.

1.7.4. Cancer and Self-Efficacy

Due to improvements in detection and effective treatments, cancer is increasingly being viewed as a chronic illness (Beckham et al., 1997). Researchers are now beginning to consider the various roles self-efficacy has in cancer populations (Beckham et al., 1997; Manne et al., 2006). For instance, it has been examined in relation to participation in screening behaviour (Carpenter & Colwell, 1995; Tolma, Reininger, Evans & Ureda, 2006). Tolma and colleagues (2006) found self-efficacy to be a strong predictor of intention to obtain an initial screening mammogram. Carpenter and Colwell (1995) add to this finding suggesting that increased knowledge is associated with increased self-efficacy for cancer screening. Knowledge appears to be important when considering self-efficacy in cancer patients (LaCoursiere, Knobf & McCorkle, 2005); this study found that knowledge gained from accessing information
online enhanced self-efficacy: this could empower individuals to participate in their own care, resulting in adjustment to the condition (LaCoursiere et al., 2005).

Further application of the theory has been demonstrated by Cunningham, Lockwood and Cunningham (1991); the study found strong positive correlations between self-efficacy and quality of life and self-efficacy and mood in cancer patients (Cunningham et al., 1991). Furthermore, a brief coping skills intervention led to improvements in all three. These findings tie in appropriately with earlier discussions regarding the usefulness of self-efficacy in self-management interventions. In breast cancer patients undergoing chemotherapy, interventions enhancing self-efficacy led to increases in quality of life and decreased symptom distress (Lev et al., 2001). These results indicate that it may be most beneficial (for patients) to employ self-efficacy enhancing strategies as early as possible (diagnosis / treatment stage): this could have far-reaching implications for self-management and adjustment.

Domain-specific self-efficacy has also been investigated in cancer patients. De Boer et al. (1998) studied the role of physical self-efficacy in head and neck carcinoma patients. Patients perceiving themselves as more physically efficacious were more likely to survive and less likely to have disease recurrence (de Boer et al., 1998). It is suggested that those with more positive physical self-efficacy beliefs would be in a better position (in terms of fitness) to cope with illness stresses (Thornton, Rychman, Robbins & Donolli, 1987). Evidence for this can be seen within the context of treatment whereby it could be expected that high physical self-efficacy patients handle treatment side-effects better (Morrow, 1992). Additional research has reported highly physically efficacious patients experienced fewer concerns regarding treatment and consequences of cancer (de Boer et al., 1995). Jerusalem and Schwarzer (1992) corroborate these findings demonstrating that persons with high physical self-efficacy were less likely to exhibit fear, worry and anxiety when faced with difficult situations. Consequently, possessing the necessary beliefs to cope with such situations could lead to increased chances of survival.
Future research needs to examine the role of self-efficacy in other aspects of illness management among cancer patients such as resuming everyday activities including returning or maintaining work after a cancer diagnosis.

1.7.5. Self-Efficacy and Cancer Psychosocial Adjustment

Cancer patients need to adjust to the impact and potential consequences of their disease; consequently, researchers need to consider how such a diagnosis could affect patients emotionally and socially (i.e. psychosocial adjustment) (Irvine et al., 1991). A number of studies have examined the role of self-efficacy in the adjustment to cancer. Self-efficacy theory assumes that the greater confidence people have in their ability to execute specific actions, the greater the probability of attaining their goals (Bandura, 1977; 1997). The literature suggests higher coping self-efficacy is associated with better adjustment and more positive quality of life outcomes in cancer patients (Beckham et al., 1997; Lev, Paul & Owen, 1999; Lev et al., 2001). However, the precise role of self-efficacy in adjustment to cancer is somewhat unclear (Lev et al., 2001; Rancor et al., 2002; Schulz & Mohamed, 2003; Kreitler, Peleg & Ehrenfeld, 2007). In breast cancer patients, studies have found a positive relationship between self-efficacy and psychosocial adjustment (e.g. experience fewer symptoms whilst having chemotherapy) (Arora et al., 2002; Lev et al., 2001). In evaluation, these studies comprised of a small sample and were cross sectional (Lam & Fielding, 2007). Schulz and Mohamed (2003) found relationships between self-efficacy, social support and benefit finding. Research refuting the role of self-efficacy in adjustment suggested that self-efficacy was not a pre-disease predictor of adjustment to cancer (Rancor et al., 2002). Thus, findings regarding the role of self-efficacy are inconsistent. It could be argued that methodological factors such as the use of different measures may account for these differences.

In response, Kreitler et al. (2007) sought to delineate some of the existing ambiguities; they utilised structural equation modelling to examine the effects of different stressors (perceived stress and self-efficacy) on quality of life outcomes. Results indicated that self-efficacy impacted upon perceived stress which in turn impacted upon quality of life. However, self-efficacy was also
found to have a direct effect on quality of life (the higher self-efficacy = more positive quality of life). Therefore, such findings suggest that to aid adjustment, self-efficacy needs to be engaged (along with other mechanisms e.g. social support) (Kreitler et al., 2007). Inevitably, this would lead to a decrease in perceived stress and better adjustment. The important point to keep in mind is that self-efficacy is unlikely to operate alone when influencing various health behaviours.

In sum, self-efficacy theory has been applied successfully to a variety of areas. The theory offers an insight into why some people more than others may be more successful in performing certain behaviours. Appropriate interventions have been designed and successfully delivered to those possessing lower perceived self-efficacy beliefs. Thus, the principles of the theory seem to drive individuals’ lives in many ways. With regard to self-efficacy and cancer, research is still required in the area. Understanding the complex effects self-efficacy has upon processes of adjustment and so on are still in their infancy. Research now needs to unpick how perceived self-efficacy impacts upon wider aspects of an individual’s life, for example, employment decisions and return to work intentions in cancer patients. Considering both illness and work self-efficacy in this population would provide a richer insight into the adjustment and management of cancer over time.

1.8. Summary

To conclude this chapter, it is evident that a cancer diagnosis can lead to a number of physical effects and psychosocial impacts. The literature has provided a plethora of results indicating that treatment effects such as nausea and psychosocial impacts like depression and fatigue are likely to influence quality of life outcomes including the quality of working life. However, the role of social support and self-efficacy is somewhat unclear, particularly in relation to work outcomes. The literature discussed suggests that these factors are likely to be important when attempting to understand colorectal cancer patients’ disease management, work ability and employment outcomes. Further to this, some existing research is limited as samples comprise of various cancer types where much time has elapsed since individuals’ diagnosis.
Chapter 2

2. Cancer and Employment: Literature Review

2.1. Introduction

This chapter will discuss the existing literature relating to how cancer can impact upon employment outcomes, particularly in relation to work ability and return to work. Many cancer survivors are likely to have been employed at the time of diagnosis; therefore, for some of this group, returning to work is of more significance to some patients than others. A proportion may return to work due to financial loss (Barofsky, 1989), whereas others may feel that work benefits them psychologically (improved self-esteem) (Hakkaart-van Roijen, 1998). This chapter will consider research that has concerned itself with investigating absence from work, particularly in relation to diagnosis and treatment. There will then be some discussion considering the return to work amongst cancer patients: this will focus on cancer type, treatment and person-related factors. Finally, established research into the work ability of cancer patients re-entering the workplace will be discussed and evaluated.

2.2. Work Absence: The Impact of Diagnosis and Treatment

The impact of diagnosis and treatment on ability to work (sickness absence) is well documented in the literature (Morrell & Pryce, 2005; Bradley et al., 2005; Bradley, Oberst & Schenk, 2006; Pryce, Munir & Haslam, 2007; Amir et al., 2007). Studies suggest that approximately 40% of all cancer patients take time off work during treatment and recovery (Short et al., 2005). More recently, Pryce et al. (2007) established 70% of 328 respondents did not work during treatment. Evidence suggests that the detrimental impact of cancer on work absence can continue for a number of years after diagnosis (Taskila-Abrandt et al., 2004) and may vary according to cancer site. For example, when considering those diagnosed with breast cancer, it is estimated that between 62% and 84% will take time off work during treatment (Maunsell et al., 1999; Short et al., 2005). Little information is available on colorectal cancer; however, Choi et al. (2007) studied job loss and reemployment in a sample of stomach,
liver and colorectal cancer patients from Korea (over a 24 month period). For colorectal patients, 46% stopped working compared to 48% with stomach and 63% with liver cancer whilst undergoing treatment. However, this study comprised of male cancer patients only; it is, therefore, unlikely to represent the general population of cancer survivors (Choi et al., 2007). In a sample of prostate cancer patients, treatment was associated with sickness absence up to six months post-diagnosis (Bradley et al., 2005). At 12 months, 30% of these individuals reported a work limitation associated with their cancer and treatment (Bradley et al., 2005b). In a later study, Bradley et al. (2006) recruited patients six months post-diagnosis and found an association between cancer treatment and absence. For breast cancer patients, those treated surgically missed an average 26.5 days from work; this rose to 68.5 days for those undergoing surgery, chemotherapy and radiotherapy. For men diagnosed with prostate cancer, the study found an average absence of 33 days in those that underwent surgery alone; for those that underwent surgery, together with chemotherapy or radiotherapy, this rose to 40 days and finally, the lowest rate of absence was observed in those who underwent radiotherapy alone (9.5 days) (Bradley et al., 2006).

For treatment, the impact on sickness absence is likely to be greater in those undergoing more than one treatment modality (Bradley et al., 2006). Amir et al. (2007) conducted a study in the UK and also found significant differences in duration of sick leave according to treatment modality: 83% of those receiving surgery returned to work in less than six months following diagnosis whereas only 47% of those who received a combination of surgery and radiotherapy, chemotherapy or hormone therapy returned to work less than six months post-diagnosis. Further to this, Amir et al. (2007) reported from their sample that females were more likely to take 6 -12 months sick leave compared with males (33% of women as opposed to 18% of men). Males were more likely to take sick leave lasting at least a year (18% of men as opposed to 10% of women). However, a limitation of this study is that gender was unevenly distributed and almost half of the sample (48%) comprised of respondents with breast cancer (Amir et al., 2007).
Therefore, despite a lack of information related to absence following a colorectal cancer diagnosis, existing findings suggest that it is likely that those undergoing more than one type of treatment may take more time off than an individual receiving just one form of treatment. However, differences in employment outcomes according to cancer type make it difficult to envisage the precise impact a colorectal cancer diagnosis may have upon these outcomes. Moreover, differences in the nature of symptoms (e.g. altered bowel habits after surgery) and side effects according to cancer type and treatment type make it difficult to apply existing findings to colorectal cancer patients.

2.3. Return to Work Following Cancer

Improvements in cancer detection and treatment have led to improvements in cancer recovery, resulting in resumption of everyday activities including work. Returning to work is often deemed to be a marker of recovery and a regaining of a sense of normalcy for patients (Spelten et al., 2002; Kennedy et al., 2007). However, others may return to work due to a potential loss or change to their health insurance (Choi et al., 2007). Within the cancer literature, return to work and work continuance statistics vary immensely as many studies have utilised different methods, designs and differing cancer populations (Spelten et al., 2002; Bushunow, Sun, Raubertas & Rosenthal, 1995; Maunsell et al., 1999). Evidence suggests that a number of those diagnosed with cancer continue to work during treatment; for example, a cross-sectional retrospective study of 328 cancer patients and survivors revealed that 30% continued to work throughout treatment and even more returned to work upon completion of treatment (Pryce et al., 2007).

Table 2.1 summarises return to work rates reported in the literature. Studies comprising of cancer patients and survivors indicate that return to work rates range between 27% (Bergman & Sorenson, 1987) and more recently to 94% (Balak et al., 2008). The prior rate is based on a lung cancer sample, which is associated with a poor prognosis; thus, returning to work would be less likely in this group (Cancer Research UK, 2007). In a review of 14 studies comprising different cancer types, Spelten et al. (2002) reported that the mean rate of return to work was 62% (range 30% - 93%); this review was the important
### Table 2.1: Summary of return to work / work continuance studies.

<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Design</th>
<th>Cancer Type (N, n)</th>
<th>Return to Work Rate (%)</th>
<th>Point of Return to Work</th>
<th>Factors associated with Return to Work</th>
</tr>
</thead>
<tbody>
<tr>
<td>Balak et al. (2008)</td>
<td>Longitudinal</td>
<td>Breast cancer (N = 72)</td>
<td>94%</td>
<td>65% continued or returned to work within a year. 94% continued or returned to work within 2 years of diagnosis.</td>
<td>Treatment (chemotherapy or multimodal treatment).</td>
</tr>
<tr>
<td>Bouknight et al. (2006)</td>
<td>Longitudinal</td>
<td>Breast cancer (N = 416)</td>
<td>81%</td>
<td>82% returned to work at 12 months (26 of these stopped working at 18 months). 81% returned to work at 18 months.</td>
<td>Income, advanced disease, manual labour, heavy lifting, employer discrimination, older age, black race, less educated and fair/poor health at diagnosis.</td>
</tr>
<tr>
<td>Buchmann et al. (2003)</td>
<td>Cross-sectional</td>
<td>Leukaemia and lymphoma (N = 163)</td>
<td>70%</td>
<td>70% returned to work within two years of transplantation.</td>
<td>Pain, anxiety, sleep disorder, depression, impaired social function, partnership and family life.</td>
</tr>
<tr>
<td>Buckwalter et al. (2007)</td>
<td>Longitudinal</td>
<td>Head and neck cancer (n = 666; employed prior to treatment n = 239)</td>
<td>40%</td>
<td>40% returned to work within first year.</td>
<td>Advanced disease, multimodal treatment, older age, fatigue and pain.</td>
</tr>
<tr>
<td>Author (year)</td>
<td>Design</td>
<td>Cancer Type ((N, n))</td>
<td>Return to Work Rate (%)</td>
<td>Point of Return to Work</td>
<td>Factors associated with Return to Work</td>
</tr>
<tr>
<td>--------------</td>
<td>-----------------</td>
<td>----------------------------------------------------------------------------------------</td>
<td>-------------------------</td>
<td>-------------------------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td>Bushunow et al. (1995)</td>
<td>Longitudinal retrospective</td>
<td>Breast cancer ((N = 145;) two groups chemotherapy (n = 76) and not receiving chemotherapy (n = 69))</td>
<td>93%</td>
<td>92% of those receiving chemotherapy returned to work within 12 months. 94% of those not receiving chemotherapy returned to work within 12 months</td>
<td></td>
</tr>
<tr>
<td>de Boer et al. (2008)</td>
<td>Longitudinal</td>
<td>Various ((N = 195))</td>
<td>64%</td>
<td>24% continued to work or returned to work at six months, 50% continued to work or returned to work at 12 months and 64% continued to work or returned to work at 18 months.</td>
<td>Work ability, physical work ability, mental work ability and treatment.</td>
</tr>
<tr>
<td>de Lima et al. (1997)</td>
<td>Cross-sectional</td>
<td>Acute Myeloid Leukaemia (AML) ((N = 215))</td>
<td>74% &lt;50 years</td>
<td></td>
<td>Age.</td>
</tr>
<tr>
<td>Edman et al. (2001)</td>
<td>Cross-sectional</td>
<td>Chronic leukaemia, acute leukaemia and lymphoma ((N = 25))</td>
<td>85%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Estey et al. (1997)</td>
<td>Cross-sectional</td>
<td>Acute Myeloid Leukaemia (AML) ((n = 215; working n = 155))</td>
<td>66%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author (year)</td>
<td>Design</td>
<td>Cancer Type (N, n)</td>
<td>Return to Work Rate (%)</td>
<td>Point of Return to Work</td>
<td>Factors associated with Return to Work</td>
</tr>
<tr>
<td>-----------------------</td>
<td>-----------------</td>
<td>----------------------------------------</td>
<td>-------------------------</td>
<td>-------------------------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td>Gruber et al. (2003)</td>
<td>Cross-sectional</td>
<td>Leukaemia (N = 163)</td>
<td>60%</td>
<td></td>
<td>Pain, anxiety, sleep disorders, depression, impaired social functioning, partnership and family life</td>
</tr>
<tr>
<td>Jacoulet et al. (1997)</td>
<td>Longitudinal</td>
<td>Small cell lung cancer (N = 155; working n = 77)</td>
<td>40%</td>
<td>40% continued with or returned to work within 24 months.</td>
<td></td>
</tr>
<tr>
<td>Johnsson et al.</td>
<td>Prospective</td>
<td>Breast cancer (N = 270)</td>
<td>86%</td>
<td>79% continued or returned to work within 12 months, 24 months 84% continued or returned to work and at 36 months 86% continued or returned to work.</td>
<td>Adjuvant endocrine therapy and chemotherapy / nodal status.</td>
</tr>
<tr>
<td>Kennedy et al. (2007)</td>
<td>Qualitative</td>
<td>Breast cancer, non-Hodgkin's Lymphoma, uterus cancer, larynx (N = 29)</td>
<td>93%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lee et al. (2008)</td>
<td>Cross-sectional and retrospective</td>
<td>Stomach cancer (n = 408); plus disease free control group (n = 994)</td>
<td>54%</td>
<td></td>
<td>Fatigue and treatment.</td>
</tr>
</tbody>
</table>
## Chapter 2

### Cancer and Employment: Literature review

<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Design</th>
<th>Cancer Type (N, n)</th>
<th>Return to Work Rate (%)</th>
<th>Point of Return to Work</th>
<th>Factors associated with Return to Work</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main et al (2005)</td>
<td>Qualitative</td>
<td>Various (N = 28)</td>
<td>86%</td>
<td></td>
<td>Pain, nausea, fatigue impacted ability to work, thus work decisions.</td>
</tr>
<tr>
<td>Pryce et al. (2007)</td>
<td>Cross-sectional</td>
<td>Various (N = 328)</td>
<td>30% continued to work through treatment; 42.3% returned to work after treatment</td>
<td></td>
<td>Pain, stress, physical changes, employer return to work meeting, doctor’s advice, work flexibly.</td>
</tr>
<tr>
<td>Spelten et al. (2002)</td>
<td>Review</td>
<td>Various (N = 1904)</td>
<td>30 to 93% (mean 62%)</td>
<td>Age, work factors, disease and treatment and person-factors.</td>
<td></td>
</tr>
<tr>
<td>Spelten et al. (2003)</td>
<td>Longitudinal</td>
<td>Various (n = 235)</td>
<td>64%</td>
<td>Age and physical workload.</td>
<td>24% returned to work at 6 months, 50% returned to work at 12 months and 64% returned to work at 18 months.</td>
</tr>
<tr>
<td>Author (year)</td>
<td>Design</td>
<td>Cancer Type (N, n)</td>
<td>Return to Work Rate (%)</td>
<td>Point of Return to Work</td>
<td>Factors associated with Return to Work</td>
</tr>
<tr>
<td>--------------</td>
<td>----------------</td>
<td>------------------------------------------</td>
<td>-------------------------</td>
<td>-------------------------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td>Steiner et al. (2008)</td>
<td>Cross-sectional</td>
<td>Various (N = 100)</td>
<td>92%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sultan et al. (2006)</td>
<td>Longitudinal</td>
<td>Prostate cancer (N = 537)</td>
<td>50%</td>
<td>50% returned to work within 14, 21 and 30 days within being discharged.</td>
<td>Age, disease, occupation and marital status.</td>
</tr>
<tr>
<td>Suzuki-Tsunoda et al. (2002)</td>
<td></td>
<td>Adult acute leukaemia (N = 42)</td>
<td>48%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Syrjala et al. (2004)</td>
<td>Longitudinal</td>
<td>Leukaemia and lymphoma (n = 315)</td>
<td>84% survivors without recurrence</td>
<td>84% returned to work within 5 years.</td>
<td></td>
</tr>
<tr>
<td>Taskila-Abrandt et al. (2004)</td>
<td>Cross-sectional</td>
<td>Various (N = 12,542)</td>
<td>64%</td>
<td>64% returned to work within 2-3 years post diagnosis.</td>
<td>Cancer type and age.</td>
</tr>
<tr>
<td>Taskila-Abrandt et al. (2005)</td>
<td>Cross-sectional</td>
<td>Various (n = 46,312) (and control group)</td>
<td>50%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yokoyama et al. (1985)</td>
<td>Cross-sectional</td>
<td>Rectal cancer (N = 34)</td>
<td>47%</td>
<td></td>
<td>Surgery type.</td>
</tr>
</tbody>
</table>
## Cancer and Employment: Literature review

<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Design</th>
<th>Cancer Type ((N, n))</th>
<th>Return to Work Rate (%)</th>
<th>Point of Return to Work</th>
<th>Factors associated with Return to Work</th>
</tr>
</thead>
<tbody>
<tr>
<td>Van der Wouden et al. (1992)</td>
<td>Cross-sectional</td>
<td>Various ((N = 849))</td>
<td>44%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weis et al. (1992)</td>
<td>Cross-sectional</td>
<td>Various ((N = 380))</td>
<td>33%</td>
<td></td>
<td>Age, tumour stage, prognosis and former work status.</td>
</tr>
</tbody>
</table>
milestone in the area of cancer and work research and identified areas for future researchers. Consequently, a more recent review of 12 cancer and work ability studies between 2002 and 2007, reports return to work rates ranging between 41% and 84% (Taskila & Lindbohm, 2007). A substantial amount of return to work literature focuses on breast cancer patients; return to work rates range between 80% and 94% in these studies (Bushunow et al., 1995; Hinman, 2001; Drolet et al., 2005; Bouknight, Bradley & Luo, 2006; Johnsson et al., 2007; Balak et al., 2008). Even though breast cancer is the most commonly diagnosed cancer in women and these results are useful, they are not representative of cancer sufferers in general.

The literature also provides some information relating to the time taken to return to work, which is also summarised in Table 2.1. In a recent prospective study ($N = 195$), de Boer and colleagues (2008) found 24% continued or returned to work within 6 months of diagnosis; at 12 and 18 months this rose to 50% and 64% respectively. Such results are perhaps unsurprising as it is likely that treatment patterns soon after diagnosis make it difficult to continue with work. Furthermore, as more time has elapsed since diagnosis and treatment, the likelihood of returning to work increases. The most favourable return to work outcomes have been found in studies comprising of breast cancer patients (Balak et al., 2008; Bouknight et al., 2006; Johnsson et al., 2007). However, this may be a reflection of the variety of studies that have sought to investigate this group as opposed to other cancer types. In short, from such return to work rates reported in the literature, it is feasible to suggest that return to work is an attainable outcome for the majority of cancer patients. Moreover, differences in return to work are likely to be associated with a number of factors including treatment type, age and job type.

### 2.3.1. Factors Related to Return to Work

A number of factors correlated with return to work have been identified, including: cancer type (Spelten et al., 2002; Taskila-Abrandt et al., 2004; Shultz, Beck, Stava & Sellin, 2002; Short et al., 2005; Taskila-Abrandt et al., 2005); fatigue (Spelten et al., 2002; Spelten et al., 2003); depression, poor social
support (Berry, 1993); treatment factors (Spelten et al., 2002); person-related factors such as age and education (Lima et al., 1997; Maunsell et al., 1999), and work-factors such as job type (Maunsell et al., 1999; Spelten et al., 2002; Main et al., 2005; Ehrmann-Feldman et al., 1987). However, according to some, the existing literature has not offered enough insight into how the identified problems could be rectified (Steiner et al., 2004).

For example, when considering cancer type, return to work rates are high in testicular cancer patients and low in head and neck cancer patients (Spelten et al., 2002; Taskila-Abrandt et al., 2004). Higher return to work rates in testicular patients could be attributed to diagnosis occurring at a younger age when compared with other cancer types (e.g. prostate cancer); furthermore, due to successful treatments, survival rates associated with this group are also high (Taskila-Abrandt et al., 2004).

Differences in return to work rates have also been reported according to age (person-related factor) (Lima et al., 1997). Lima et al. (1997) found for those aged 50 years or less return to work was 74%; however, for those over the age of 50 years return to work was 30 per cent. In spite of this, recent economic trends suggest that increased life expectancy has inevitably altered the demographic make-up of the work-force: hence, there are many more ageing workers than previously (Riche, 2001 as cited in Sanchez & Richardson, 2006). In response to this, Governments are striving to keep people working for longer (Munir, Khan, et al., 2009). Subsequently, it can be argued that many people may not retire at the statutory age of 65 years for men and 60 years for women as was common in previous generations (Sanchez & Richardson, 2006; Amir et al., 2007). Furthermore, increased national and international investment in colorectal screening and detection programmes will lead to improved life expectancy for working-aged colorectal cancer patients who will subsequently require support when resuming work.

At present, there is very little information concerning employment outcomes for those managing colorectal cancer. Return to work rates and factors predicting return to work for those affected by colorectal cancer are presented in Table
2.2. Two early studies by Feldman (1976; 1978) demonstrated that return to work rates were 74% and 75% in this group. Schultz and colleagues (2002) found 67% of colon cancer survivors had returned to work five years post diagnosis. In evaluation, this study was cross-sectional and therefore it is difficult to suggest factors predicting return to work; instead, it would be more worthwhile to recruit and follow patients soon after diagnosis. Ultimately, such an approach would help to identify the barriers that may prevent returning to work immediately following diagnosis. A recent study has contributed to these earlier findings; Sanchez and Richardson (2006) report an 89% return to work rate for colorectal cancer patients and 64% returned within two months of diagnosis. Hence, a noticeable improvement when compared with the return to work rates as reported by Feldman (1976; 1978). Eighty per cent of those who did not return to work attributed it to health or medical reasons (Sanchez & Richardson, 2006): this is consistent with Hewitt, Rowland and Yancik (2003) who found that multiple co-morbidities increased the likelihood of work limitations or disability (various cancer types) when compared with survivors without co-morbidity.

Some of the factors associated with the unlikelihood of returning to work included treatment, marital status and work-factors such as poor support from an employer (Sanchez, Richardson & Mason, 2004; Sanchez & Richardson, 2006). These researchers also report that chemotherapy was the greatest predictor of work delay when compared with person and work-related factors. However, the cross-sectional nature of this study renders it difficult to ascertain if these results are attributable to actual chemotherapy effects (e.g. fatigue) or the actual time period of the treatment regime (Sanchez & Richardson, 2006). Therefore, the authors suggest prospective studies of colorectal cancer patients would be ideal, especially to inform intervention design (Sanchez & Richardson, 2006).
Table 2.2: Summary of colorectal cancer return to work / work studies.

<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Design</th>
<th>Sample (N, n)</th>
<th>Summary of Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Choi et al. (2007)</td>
<td>Prospective</td>
<td>Colorectal cancer (n = 91); stomach cancer (n = 97); liver cancer (n = 117)</td>
<td>46% of colorectal cancer patients lost their job within 3 months of diagnosis. Of these, 31% were later reemployed within 24 months. Age, education, income, stage and cancer site (whole sample).</td>
</tr>
<tr>
<td>Feldman (1976)</td>
<td>Cross-sectional</td>
<td>Various (N = 92) (included colon or rectum) all white collar workers</td>
<td>74% returned to work.</td>
</tr>
<tr>
<td>Feldman (1978)</td>
<td>Cross-sectional</td>
<td>Various (N = 107; colon or rectum n = 38) all blue collar workers</td>
<td>75% returned to work. Participants were concerned about frequent toilet use. Time lost from work was higher than for those with other cancer types; 68% reported absence of 9 weeks or more.</td>
</tr>
<tr>
<td>Sanchez et al. (2004)</td>
<td>Cross-sectional</td>
<td>Colorectal cancer (N = 250; employed 80%)</td>
<td>89% of those that were employed at diagnosis returned to work. Of these 81% remained employed for five years post-diagnosis. However, 34% delayed their return to work for longer than two months post diagnosis due to chemotherapy treatment.</td>
</tr>
<tr>
<td>Sanchez et al. (2006)</td>
<td>Cross-sectional</td>
<td>Colorectal cancer (N = 250; employed n = 143)</td>
<td>Those in employment were in better health when compared with those who were not. The presence of co-morbidity, support and employment status was associated with quality of life outcomes.</td>
</tr>
<tr>
<td>Schultz et al. (2002)</td>
<td>Cross-sectional</td>
<td>Various (N = 4364)</td>
<td>67% of colon cancer survivors returned to work within 5 years of diagnosis.</td>
</tr>
</tbody>
</table>
A recent prospective study is presented by Choi et al. (2007). These results showed that of the 46% of colorectal cancer patients that stopped working after diagnosis, 31% \((n = 13)\) were reemployed within 24 months, compared to 69% that were not \((n = 29)\). Such job loss was more common among older, less educated and lower income patients (Choi et al., 2007). Despite such studies, more research is needed that considers this group further, in particular little is known about the employment outcomes of colorectal cancer patients in the UK. Furthermore, existing findings are based on samples drawn from either the US (Sanchez & Richardson, 2006) or Korea (Choi et al., 2007); due to variations in working practices it is difficult to apply these findings to the UK. Consequently, it is difficult to ascertain whether colorectal cancer patients in the UK are working due to good health (physically and psychologically more able), or whether other factors are driving them to work (finances): thus the present research would aim to delineate some of these ambiguities.

It is apparent that people affected by cancer are able to work throughout treatment and a larger proportion return to work once treatment has ceased. Such research is useful as it provides insight into employment pathways and offers some detail about differences according to cancer types, treatment, psychosocial factors such as symptoms of fatigue and depression (e.g. fatigue found to predict return to work, Spelten et al., 2003) and person-related factors. Nonetheless, little is known about how cancer treatment and stoma appliances may impact upon the work outcomes of colorectal cancer patients.

### 2.4. Cancer and Work Ability

The focus of research is now moving towards considering the impact of cancer and its treatment on work ability for those who continue to work during treatment or return to work following treatment (Munir, Yarker & McDermott, 2009). A number of self-report measures assess work productivity. For example, in their review of six generic work productivity self-report measures, Prasad, Wahlqvist, Shikiar and Shih (2004) suggest that the Work Productivity and Activity Impairment (WPAI) scale and the Work Limitations Questionnaire (WLQ) have been studied extensively and have appropriate validity and reliability. The WLQ (Lerner et al., 2001) has been used to assess work
productivity in studies of depression (Lerner et al., 2004) and more recently in brain tumour survivors (Feuerstein et al., 2007). When compared with a comparison group, Feuerstein et al. (2007) found that brain tumour survivors reported lower work productivity and more time lost from work. For the purpose of this study work ability is defined as “...how able is a worker to do his or her job with respect to the work demands, health and mental resources,” (Ilmarinen, Tuomi & Seitsamo, 2005, p. 3). Whilst some people affected by cancer are able to continue working in a similar manner prior to diagnosis, for others, this is not always the case.

Some experience impairments in their ability to work which are attributable to their illness and treatment (Taskila et al., 2007); such impairments can lead to decrements in work ability (Short, Vasey & Moran 2008a; Short, Vasey & BeLue, 2008b; Bouknight et al., 2006; Taskila, et al., 2007) and even an inability to work (some do not resume / return to work) (Hewitt et al., 2003). In a review of 12 studies investigating employment and work ability in cancer survivors, Taskila and Lindbohm (2007) suggest impairments in work ability range from 21% and 31 per cent. Research suggests cancer patients with the highest perceptions of work ability are most likely to work during treatment (Taskila et al., 2007; de Boer et al., 2008). However, when compared with those without cancer and other chronic conditions, it has been suggested that cancer survivors report poorer levels of health (Hewitt et al., 2003; Gudbergsson, Fossa, Sanne & Dahl, 2007) and lower work ability (Short et al., 2008b; de Boer et al., 2008).

Table 2.3 summarises 22 studies that have considered the impact of cancer upon work ability, work productivity and work adjustments due to cancer and reduced work ability. Compared with a healthy control group, those diagnosed with malignant brain tumours (Feuerstein et al., 2007), stomach (Lee et al., 2008), breast, prostate, and testicular cancers (Maunsell et al., 1999; Bradley et al., 2007; Gudbergsson et al., 2007; Gudbergsson, Fossa & Dahl, 2008) reported reduced work productivity and work ability: this included both mental and physical work ability and adjustments to their work practices. However, in another study, perceived work ability rates in employed cancer survivors
(n = 595) and disease free controls (n = 757) were similar (Taskila et al., 2007). Similarly, in a longitudinal study of prostate cancer patients and healthy controls no difference between hours worked was found, thus suggesting that work ability may have been similar in both groups (Bradley et al., 2007). However, survivors reported decrements in both physical (26%) and mental work ability (19%) due to cancer (Taskila et al., 2007); this finding is supported further in a sample of breast and testicular cancer survivors (Gudbergsson et al., 2007).
Table 2.3. Summary of Work Ability studies.

<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Study Design</th>
<th>Cancer Type (N, n)</th>
<th>Work Ability Measure</th>
<th>Summary of Findings</th>
<th>Factors Associated with Work Ability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amir et al. (2008)</td>
<td>Qualitative</td>
<td>Various (N = 41)</td>
<td></td>
<td>Fatigue, cognitive limitations and loss of confidence impacted work ability negatively. Work adjustments such as reduced hours helped to manage such decrements in work ability.</td>
<td>Fatigue and cognitive limitations.</td>
</tr>
<tr>
<td>Bradley et al. (2007)</td>
<td>Longitudinal</td>
<td>Breast cancer (n = 496); Prostate (n = 294); healthy controls (n = 300)</td>
<td>Weekly hours</td>
<td>Greatest difference between hours worked between breast cancer and controls seen at 6 months. Treatment-related impairments observed in both cancer groups, however more pronounced in breast cancer sample.</td>
<td>Treatment.</td>
</tr>
<tr>
<td>de Boer et al. (2008)</td>
<td>Longitudinal</td>
<td>Various (n = 195)</td>
<td>Work Ability Index (first three items)</td>
<td>Work ability improved over time from 4.6 (6 months) to 6.3 (12 months) and 6.7 (18 months) for all cancers. Work ability by gender improved for both over time but more for women. Current work ability, physical work ability and mental work ability all correlated with return to work at 18 months.</td>
<td>Cancer type, treatment and return to work.</td>
</tr>
<tr>
<td>Feuerstein et al. (2007)</td>
<td>Cross-sectional</td>
<td>Malignant brain tumour (n = 95); healthy control group (n = 131)</td>
<td>Work limitations questionnaire</td>
<td>Cancer group reported higher level of work limitations than non-cancer group.</td>
<td>Depressive symptoms, fatigue, cognitive limitations sleep and</td>
</tr>
<tr>
<td>Author (year)</td>
<td>Study Design</td>
<td>Cancer Type ((N, n))</td>
<td>Work Ability Measure</td>
<td>Summary of Findings</td>
<td>Factors Associated with Work Ability</td>
</tr>
<tr>
<td>----------------------</td>
<td>--------------</td>
<td>--------------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Fobair et al. (1986)</td>
<td>Cross-sectional</td>
<td>Hodgkin’s disease ((N = 403))</td>
<td>Number of hours worked</td>
<td>Difficulties at work reported by 42% and hours worked highly correlated with less depression, younger age and return of energy.</td>
<td>Depression, age and energy levels.</td>
</tr>
<tr>
<td>Gudbergsson et al. (2007)</td>
<td>Cross-sectional</td>
<td>Breast cancer ((n = 208)); testicular or prostate cancer ((n = 209)); healthy controls ((n = 417))</td>
<td>Demand control support questionnaire, weekly hours, changes in job tasks ((yes/no))</td>
<td>Survivors who had completed primary treatment did not differ in job situation or occupational stress when compared with controls. However, females reported more job strain. Mental and physical work capacity however, was impacted in survivors.</td>
<td>Gender, age, personality and anxiety.</td>
</tr>
<tr>
<td>Gudbergsson et al. (2008)</td>
<td>Cross-sectional</td>
<td>Breast cancer ((n = 219)); testicular cancer ((n = 150)); prostate cancer ((n = 62))</td>
<td>Work changes including employer, occupation, work tasks, unemployment and pension. Work Ability Index</td>
<td>Those who made changes to work had poorer work ability and reduced mental and physical work ability.</td>
<td>Work change, age, symptoms, co-morbidity, support, neuroticism and physical and mental quality of life.</td>
</tr>
<tr>
<td>Henry et al. (2008)</td>
<td>Cross-sectional</td>
<td>Various ((N = 841)) receiving chemotherapy or radiotherapy</td>
<td>Missed work days (past year) due to treatment and treatment-related side-effects</td>
<td>Employed patients missed on average 18 days (over 12 months) due to treatment side effects. 88% reported at least one side-effect (fatigue most commonly reported)</td>
<td>Treatment and number of side effects.</td>
</tr>
<tr>
<td>Author (year)</td>
<td>Study Design</td>
<td>Cancer Type ((N, n))</td>
<td>Work Ability Measure</td>
<td>Summary of Findings</td>
<td>Factors Associated with Work Ability</td>
</tr>
<tr>
<td>-----------------------</td>
<td>--------------</td>
<td>----------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>--------------------------------------</td>
</tr>
<tr>
<td>Kennedy et al. (2007)</td>
<td>Qualitative</td>
<td>Various ((N = 29))</td>
<td>Work ability measure</td>
<td>A third reported they were concerned about their reduced work capability and found it difficult to concentrate and cope at work. Fatigue was difficult to manage at work. Employer support and adjustments helped gradual resumption of work.</td>
<td></td>
</tr>
<tr>
<td>Kessler et al. (2001)</td>
<td>Cross-sectional</td>
<td>Various chronic conditions (n = 2074) including cancer</td>
<td>Out of past 30 days totally unable to work or perform normal activities because of health problems (work-loss days) and work-cut-back days</td>
<td>Cancer group showed greatest impairments in work (average 16.4 days lost).</td>
<td>Fatigue.</td>
</tr>
<tr>
<td>Lee et al. (2008)</td>
<td>Cross-sectional</td>
<td>Stomach cancer (n = 408); healthy controls (n = 994)</td>
<td>Work-related difficulties included reduced hours and work-related disability (compared to pre-diagnosis), fatigue and exhaustion</td>
<td>Cancer survivors greater risk of reduced hours and lessened work-related ability and were more easily fatigued and exhausted than controls.</td>
<td>Fatigue and exhaustion.</td>
</tr>
<tr>
<td>Main et al. (2005)</td>
<td>Qualitative</td>
<td>Various (N = 28); working (n = 27)</td>
<td></td>
<td>Due to the impact of pain, fatigue nausea participants reduced hours, altered job tasks, changed employer to manage</td>
<td></td>
</tr>
</tbody>
</table>
## Chapter 2

### Cancer and Employment: Literature review

<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Study Design</th>
<th>Cancer Type ((N, n))</th>
<th>Work Ability Measure</th>
<th>Summary of Findings</th>
<th>Factors Associated with Work Ability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maunsell et al. (1999)</td>
<td>Qualitative</td>
<td>Breast ((N = 13))</td>
<td></td>
<td>Reduced work ability (both mental and physical).</td>
<td>Age, co-morbidity and chemotherapy.</td>
</tr>
<tr>
<td>Mols et al. (2009)</td>
<td>Cross-sectional</td>
<td>Various ((N = 403))</td>
<td>Current work situation, weekly hours and whether changes in work situation were attributable to cancer</td>
<td>Some reduced their hours ((n = 69)) due to effects of cancer. Being older, having more than one co-morbidity, chemotherapy and disease progression were predictors of work changes.</td>
<td>Age, co-morbidity and chemotherapy.</td>
</tr>
<tr>
<td>Nieuwenhuijsen et al. (2009)</td>
<td>Longitudinal</td>
<td>Various ((N = 45))</td>
<td>Work Ability Index (one item)</td>
<td>Although those with neuropsychological impairment ((n = 15)) showed lower work ability compared with no impairment this was not statistically significant.</td>
<td></td>
</tr>
<tr>
<td>Pryce et al. (2007)</td>
<td>Cross-sectional</td>
<td>Various ((N = 328))</td>
<td></td>
<td>No differences between cancer types. Fatigue made it difficult to work during treatment and following treatment.</td>
<td>Fatigue.</td>
</tr>
</tbody>
</table>
### Chapter 2

#### Cancer and Employment: Literature review

<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Study Design</th>
<th>Cancer Type ($N, n$)</th>
<th>Work Ability Measure</th>
<th>Summary of Findings</th>
<th>Factors Associated with Work Ability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rasmussen &amp; Elverdam (2008)</td>
<td>Ethnographic study including participant observation and qualitative interviews</td>
<td>Various ($N = 23$)</td>
<td></td>
<td>Due to physical and psychological side effects some participants reduced hours following treatment to manage lessened mental and physical work ability.</td>
<td></td>
</tr>
<tr>
<td>Short et al. (2008a)</td>
<td>Cross-sectional</td>
<td>Various ($n = 504$); healthy controls ($n = 3903$)</td>
<td>Weekly hours</td>
<td>Cancer group worked 3-5 hours less each week compared with healthy controls.</td>
<td>New cancer diagnosis.</td>
</tr>
<tr>
<td>Short et al. (2008b)</td>
<td>Cross-sectional</td>
<td>Various ($n = 647$); chronic condition comparison group ($n = 5988$)</td>
<td>Impairments or health problems that limited their work</td>
<td>Work disability higher in the cancer group compared with chronic condition group.</td>
<td></td>
</tr>
<tr>
<td>Steiner et al. (2008)</td>
<td></td>
<td>Various ($N = 100$)</td>
<td>Weekly hours; Occupational Role Questionnaire assessed work adjustments</td>
<td>Of those who remained in employment after treatment ($n = 92$), 42 reduced work hours (&gt;4 hours), attributed this to cancer; 12 altered job duties, 3 changed employer. No differences between cancer types. A number of physical and psychological symptoms were associated with a reduction in hours.</td>
<td>Nausea/vomiting, fatigue, depression and anxiety.</td>
</tr>
<tr>
<td>Author (year)</td>
<td>Study Design</td>
<td>Cancer Type ((N, n))</td>
<td>Work Ability Measure</td>
<td>Summary of Findings</td>
<td>Factors Associated with Work Ability</td>
</tr>
<tr>
<td>-----------------------</td>
<td>---------------</td>
<td>----------------------------------------------------------------------------------------</td>
<td>---------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-------------------------------------</td>
</tr>
<tr>
<td>Taskila et al. (2007)</td>
<td>Cross-sectional</td>
<td>Breast, testicular, prostate and lymphoma ((n = 591)); healthy controls ((n = 757))</td>
<td>Work Ability Index (one item)</td>
<td>No difference in work ability between cancer group and healthy controls. 26% of survivors reported physical work ability and 19% said mental work ability had decreased due to cancer.</td>
<td>Chemotherapy and co-morbidity.</td>
</tr>
<tr>
<td>Yabroff et al. (2004)</td>
<td>Cross-sectional</td>
<td>Various ((n = 1823)); healthy controls ((n = 5469))</td>
<td>Lost productivity due to work limitations associated with health problems and number of work days lost</td>
<td>Compared with healthy controls lost productivity was higher in cancer group.</td>
<td></td>
</tr>
</tbody>
</table>
More recently, Gudbergsson and colleagues (2008) found that survivors (breast, testicular and prostate cancers) who made changes to their work due to cancer had poorer work ability and reduced mental and physical work ability compared to survivors whose work practices remained unchanged. Such results therefore appear to indicate that survivors with poor work ability required work adjustments compared to those with moderate-to-good work ability.

Although there are only relatively few existing longitudinal studies, these have demonstrated improvements in work ability over time in those affected by cancer (Maunsell et al., 2004; Bradley et al., 2007; de Boer et al., 2008). Research by de Boer et al. (2008), utilised a sample comprised of various cancer types and were recruited between four to six months since their first day of sick leave, reported increments in perceived work ability (as measured by items taken from the Work Ability Index) over time. Work ability significantly improved over time from 4.6 (6 months), to 6.3 (12 months) and 6.7 (18 months) (de Boer et al., 2008). Similarly, a study comparing breast cancer patients and healthy controls found the greatest reduction in work hours was observed 6 months post diagnosis (breast cancer worked on average 7 hours less); however, hours worked increased at both 12 and 18 months (Bradley et al., 2007). Although the difference was not significant, breast cancer patients on average still worked 1.5 hours less than healthy controls at these two latter time points (Bradley et al., 2007). Hence, such research may seem to suggest that impairments in perceived work ability may be temporary and this can be interpreted as an encouraging finding for people affected by cancer. However, work ability deficits may persist up to 18 months after diagnosis which may result in a reduction in hours when compared with those without a history of cancer (Bradley et al., 2007).

2.4.1. Factors Impacting Work Ability

The literature suggests that levels of work ability are affected by various factors with disease recurrence (Short et al., 2005; Short et al., 2008a) and stage of cancer having been found to impact upon work ability (Short et al., 2005). Cancer type, age, education and type of job have also been reported to impact
work ability (Taskila-Abrandt et al., 2005; Taskila & Lindbohm, 2007). These findings will be discussed in the ensuing discussion.

**Cancer Type**

Cancer type has been reported to be associated with work ability (Taskila et al., 2007; de Boer et al., 2008) and employment rates (Taskila-Abrandt et al., 2004; 2005; Taskila & Lindbohm, 2007). In terms of cancer type, differences in work ability are apparent and diverse; for example, in a cross-sectional study, men diagnosed with prostate cancer reported the lowest work ability scores; whereas men diagnosed with testicular cancer showed the highest work ability scores (Taskila et al., 2007). However, when compared with testicular cancer, prostate cancers are often diagnosed in older men (Cancer Research, 2006a). Moreover, testicular cancers are highly treatable (Cancer Research, 2007) and this may explain such differences in reported work ability. Even though de Boer et al. (2008) report improvements in work ability longitudinally, differences in work ability were also identified according to cancer type. Firstly, those with haematological cancers were reported to have the most impaired work ability compared with those with genito-urological and gastrointestinal cancers who reported the least impairments in work ability. Secondly, the greatest improvements in work ability over time were reported in women with breast and genital cancers (de Boer et al., 2008). However, Yabroff et al. (2004) found that those with gastrointestinal cancers (or lung) reported the most lost productivity due to work limitations associated with cancer; this finding is not supported by de Boer et al. (2008). In response, such differences are likely to be due to diverse methods used to assess work ability. Additionally, Yabroff et al.'s study (2004) was cross-sectional, whereas de Boer et al. (2008) utilised a longitudinal approach and items from the Work Ability Index: hence, these latter findings may be considered more reliable. Closer examination of de Boer and colleagues’ (2008) results for the gastrointestinal group ($n = 23$; which would include colorectal cancer) show this group had the second highest mean scores in self-assessed work ability across all three time points (5.52, 6 months; 6.95, 12 months; 7.57, 18 months). Differences in mental and physical work ability have also been reported (Bradley et al., 2007). These researchers found
women with breast cancer reported difficulties in coping with both mentally and physically demanding work; whereas men with prostate cancer reported impairments in physically demanding work. Despite these findings, other researchers failed to find differences in work ability according to cancer type (Steiner et al., 2008). Although longitudinal study designs are increasingly being adopted, research endeavours need to attempt to consider how variables other than treatment type and fatigue may account for such differences in perceptions of work ability: this thesis aims to consider the role of self-efficacy on work ability outcomes. In addition, there is a lack of data related to the work ability of colorectal cancer patients / survivors. Furthermore, when unpicking existing results containing sub-samples of colorectal patients (e.g. de Boer et al., 2008), it is difficult as these patients often comprise the gastrointestinal group (includes stomach cancer). Consequently, it is difficult to ascertain the precise number of colorectal cancer patients that participated in the study.

Studies considering employment rates in cancer survivors compared to healthy controls are useful as it can be argued they are reflective of work ability. Furthermore, in terms of how work ability is best measured there is no consensus between existing research. Therefore, considering employment rates of cancer survivors particularly in relation to cancer type could help future work ability research design. In their review, Taskila and Lindbohm (2007) report that the probability of employment was lowest in lung cancer; however, this low employment rate is probably attributable to a poorer prognosis and survival rate associated with this cancer site. Low employment rates have also previously been reported among persons with leukaemia, stomach and cancer of the nervous system (Taskila-Abrandt et al., 2004). There was no significant difference in employment rate between those diagnosed with melanoma, non-melanoma of the skin, Hodgkin’s disease, prostate, kidney, testis or thyroid cancers and their age and gender-matched referents (Taskila-Abrandt et al., 2004). Table 2.4 summarises more recent Finnish cancer patients' (n = 46,312 diagnosed in 1997) employment status according to cancer site (Taskila-Abrandt et al., 2005); the table shows that higher employment rates (indicative of work ability), comparable with age and gender matched controls, were associated with cancers diagnosed at younger ages (testicular cancer; 67%)
compared with cancers associated with increasing age (prostate cancer; 28%). When considering colorectal patients, data is limited, however, closer examination of Taskila-Abrandt et al.'s. (2005) work identifies that employment rates were 48% for colon patients and 45% for rectum patients; therefore, lower when compared to their matched referents (51% and 48% respectively). Hewitt et al. (2003) found in a sample of 4878, the disability rate for cancer survivors was 11% (3% in controls). Results emerging from such research also indicate that work disability rates increase in those with prior cancer history, or with a co-morbidity / chronic illness (Hewitt et al., 2003; Short et al., 2008b).

**Table 2.4: Employment status of all Finnish Cancer Patients in 1997 (Taskila-Abrandt et al., 2005).**

<table>
<thead>
<tr>
<th>Cancer Site</th>
<th>% of cancer survivors</th>
<th>% of referents</th>
</tr>
</thead>
<tbody>
<tr>
<td>All cancer sites</td>
<td>50</td>
<td>55</td>
</tr>
<tr>
<td>Breast</td>
<td>54</td>
<td>56</td>
</tr>
<tr>
<td>Head &amp; neck</td>
<td>43</td>
<td>51</td>
</tr>
<tr>
<td>Digestive</td>
<td>45</td>
<td>50</td>
</tr>
<tr>
<td>Female genitals</td>
<td>48</td>
<td>52</td>
</tr>
<tr>
<td>Urinary &amp; male genitals</td>
<td>44</td>
<td>48</td>
</tr>
<tr>
<td>Skin</td>
<td>60</td>
<td>56</td>
</tr>
<tr>
<td>Testis</td>
<td>67</td>
<td>67</td>
</tr>
<tr>
<td>Lung</td>
<td>29</td>
<td>46</td>
</tr>
<tr>
<td>Nervous system</td>
<td>43</td>
<td>60</td>
</tr>
</tbody>
</table>

**Treatment and Symptoms**

Research suggests that differences in work ability are apparent according to type of treatment (Taskila et al., 2007; de Boer et al., 2008; Bradley et al., 2007; Mols, Thong, Vreugdenhil & van de Poll-Franse, 2009) and the experience of symptoms / side effects such as fatigue (Table 2.3) (Kessler et al., 2001; Henry et al., 2008).

When compared with other treatments, results indicate that chemotherapy treatment is most likely to lead to the most significant impairments in work ability; such findings are supported regardless of cancer type (Taskila et al.,
2007). Similarly, in another sample comprising of various cancer types ($N = 195$), de Boer et al. (2008) found that those receiving chemotherapy alone or a combination of either chemotherapy plus radiotherapy and/or surgery showed the lowest work ability compared with other treatment types. Recently published research also found that chemotherapy was a predictor of work changes (reduced hours) (Mols et al., 2009). However, this study’s cross-sectional approach makes it difficult to identify how long such work changes may last.

Symptoms and side-effects commonly experienced due to treatment have also been found to be associated with work ability. Symptoms such as depression, cognitive limitations, sleep problems, impaired problem solving ability and fatigue accounted for 65% of the variance associated with work limitations in a study of malignant brain tumour patients (Feuerstein et al., 2007). Henry et al. (2008) found that 88% of their sample ($N = 841$) reported at least one side-effect (fatigue most common); furthermore, the more side-effects experienced the worse the impact on work absence. Fatigue is a frequently reported side-effect in cancer patients undergoing treatment and has also been found to impact work ability negatively (Kessler et al., 2001; Feuerstein et al., 2007; Henry et al., 2008). Pryce et al. (2007) reported that symptoms of fatigue made it difficult for individuals to work during and following treatment. Furthermore, there are a number of studies that show symptoms of fatigue led to work limitations and changes in work productivity (Feuerstein et al., 2007; Pryce et al., 2007) and changes to working practices, such as reduced work hours (Amir, Neary & Luker, 2008; Bradley et al., 2007; Lee et al., 2008) and increased absence (Kessler et al., 2001). Qualitative studies have provided a useful insight into the impact of symptoms and side-effects, particularly in relation to when such effects are most pronounced (e.g. during treatment) (Kennedy et al., 2007; Amir et al., 2008), the persistence of such symptoms (Kennedy et al., 2007) and how they are managed whilst at work (Rasmussen & Elverdam, 2008). Rasmussen and Elverdam (2008) interviewed participants who stated that they reduced their hours following treatment to manage lessened mental and physical work ability. Similarly, participants interviewed by Kennedy et al. (2007) reported fatigue difficult to manage whilst at work; these problems were
manifest between two and six years following the initial diagnosis. Due to
differences in study methods and design, it is difficult to ascertain whether such
impairments, for example, fatigue caused reduced work ability.

Age, Gender and Education

A number of person-related variables (e.g. age, gender and education) have
been identified as factors that influence the work ability of cancer survivors. In
terms of age, evidence suggests impairments in work ability and changes to
work due to cancer could be exacerbated with increasing age (Fobair et al.,
1986; Taskila et al., 2007; Gudbergsson et al., 2008; Mols et al., 2009).
Subsequently, it is likely that with increasing age it may be difficult for those with
cancer to continue with or return to work after treatment. In contrast, other
research suggests work ability improves over time across various cancers
regardless of age (de Boer et al., 2008).

Regarding gender, differences in work ability have been reported. De Boer et
al. (2008) found that women had lower work ability at six months when
compared with males; however, over the course of the study women showed
the most significant improvement in work ability scores. However, these results
could be explained by cancer type as the largest sub-sample in this study was
women diagnosed with breast cancer ($n = 54$). Taskila et al. (2007) showed
that 20% of men and 28% of women felt that cancer had impaired their physical
work ability. The same study found perceived mental work ability impairments
were experienced by 23% of men and 28% of women. In another study, it
emerged that females reported higher cancer-related disabilities than men at
work (Short et al., 2005). This study also found gender differences according to
work outcomes within cancer type. For both head and neck cancers, females
were increasingly more likely than males to terminate work. These researchers
argued that explanations for such differences are unavailable at present (Short
et al., 2005).

In relation to education, Taskila-Abrandt et al. (2004) present results that
indicate that those with higher education status were more likely to be employed
after their cancer diagnosis than people with lower education status. In
addition, other research has shown that survivors with higher education levels were less likely to retire early or become unemployed than their lower educated counterparts (Abrahamsen et al., 1998; Nagarajan et al., 2003). Further to this, in a more recent study, Taskila and colleagues (2007) showed that those with higher education status perceived their work ability to be better than those with lower education status. However, such differences could be due to more educated persons participating in non-manual work as opposed to those with lower education more likely to participate in manual labour jobs. With regard to work ability, physical impairments may lead to more absence or even withdrawal from work for those in manual labour jobs (Spelten et al., 2002; Main et al., 2005).

Work-Related Factors, Adjustments and Support

Factors associated with work have been found to impact work decisions. However, little is known about how factors such as type of work, workplace adjustments and support may impact work ability (Munir, Yarker et al., 2009). For example, research tells us those in manual labour jobs experience problems when returning to work (Spelten et al., 2002; Main et al., 2005; Maunsell et al., 1999). Furthermore, Mor (1986) found a higher percentage of white-collar workers (78%) than blue collar workers (63%) remained in their jobs 12 months post diagnosis: this suggests physically demanding employment may be more difficult for cancer patients / survivors to maintain or resume.

With regard to support and workplace adjustments mixed findings are reported. Steiner et al. (2008) found that most participants informed co-workers and employers about their diagnosis. Participants reported that colleagues were either quite or extremely supportive. However, when considering the level of support received and changes to work, differences in work environment between those who reduced their hours and those who did not were not identified (Steiner et al., 2008). Alternatively, Pryce et al. (2007) found that workplace adjustments were received by less than half of those who had disclosed details of their illness to their employer. Moreover, those receiving support in terms of flexible working and work adjustments were most likely to work during treatment. Based on these findings, it is plausible to suggest that
there is a need to include health models and / or social cognitive models (e.g. self-efficacy models) in relation to cancer and work studies. The role of self-efficacy (i.e. high levels) in organisational settings and subsequent work outcomes is plentiful (e.g. Parker, 1994; Jex & Gudanowski, 1992): therefore, making use of these proven models could help towards enhancing our understanding of the employment outcomes of cancer patients and survivors.

Other studies report that individuals change their employment because they are unable to perform their job role in the way they did prior to having cancer (Main et al., 2005; Maunsell et al., 1999). A qualitative interview study found reasons for such job changes were often attributed to a lack of employer accommodations (Maunsell et al., 1999; Main et al., 2005). Studies in women diagnosed with breast cancer have reported that they experienced difficulties at work upon returning. These include job loss (Maunsell et al., 1999), reduced hours (Maunsell et al., 1999; Main et al., 2005), change in job role (Maunsell et al, 1999) and diminished physical capacity (Chirikos, Russell-Jacobs & Jacobsen, 2002; Bradley & Bednarek, 2002). Such problems may be linked to the lack of formal policy adopted by employers (Cancer Backup, 2006). Data collected from organisations suggest 73% did not have a formal procedure to manage an employee with cancer (Cancer Backup, 2006). Subsequently, as well as impairments in work ability there also appears to be a lack of knowledge inherent among employers which needs to be addressed to ensure cancer patients / survivors are supported in the workplace. However, the limited understanding of the impact of work-related factors upon work ability makes it difficult to draw such inferences at present.

2.5. Summary

In conclusion, the majority of the evidence considering how cancer may impact upon working life has come from studies from the US, Netherlands or Scandinavia. Few studies have considered cancer patients from the UK. This is concerning as approximately 90,000 of those diagnosed each year (approximately 250,000) are of working age (Morrell & Pryce, 2005). Furthermore, a substantial amount of existing research has focused purely on the experiences of those diagnosed with breast cancer (Maunsell et al, 1999;
Drolet et al, 2005; Chirikos et al., 2002; Bushunow et al, 1995; Satariano & DeLorenzo, 1996). However, as outlined in Chapter 1, along with breast cancer, colorectal cancer is among one of the top five commonly diagnosed cancers. After breast cancer (largest amount diagnosed of working age), a proportion of those diagnosed with colorectal cancer are also likely to be of a working age. The fact that colorectal cancer is associated with increasing age may explain why this group has not been considered in great detail. This however adds an interesting dimension to this particular group. Based upon ageing literature, these individuals are likely to be nearing retirement age and therefore, these patients could be more at risk of opting for ill-health / early retirement (e.g. compared with breast cancer patients). With the anticipated increase in state pension age there is a need to consider such groups as many will be able to (either by choice or need) continue with work during treatment or return after the completion of treatment (Amir et al., 2007). However, research related to this group is relatively scarce. Moreover, although research demonstrates promising return to work outcomes for this group, little is known about the work ability of these individuals. Additionally, existing research focuses on employment pathways (i.e. how many return to work) rather than the psychosocial and work factors that may influence return to work intentions, work ability and employment decisions made by people affected by colorectal cancer.

Similarly, the literature related to the physical and psychosocial impacts of cancer is vast. Factors such as fatigue, depression and social support have also been found to be related to return to work and work ability outcomes. However, although a number of factors impacting upon work outcomes have been identified, research naturally evolves searching for new areas to explore which could further enhance our understanding of a particular area. This study aimed to add to existing findings by examining the role of factors that have not previously been considered in detail. Earlier discussion highlighted the potential usefulness of self-efficacy as a factor that could be related to employment outcomes of cancer patients and survivors. Findings of cancer self-management studies (e.g. Cunningham et al., 1991; Lev et al., 2001) indicate that favourable self-efficacy perceptions are associated with positive quality of life outcomes. Subsequently, studying this construct in relation to the return to
work intentions, work ability and employment outcomes of cancer patients is worthy of consideration. This is a matter that this thesis sought to delineate. Furthermore, the role of factors such as social support upon self-efficacy beliefs was a secondary aim of this study; moreover, the research aimed to explore the extent to which work-related advice and guidance is currently being provided to patients by health professionals.

2.6. Research Objectives, Aims and Hypotheses

While there are a number of studies on cancer and work outcomes, particularly breast cancer, little information is available on employment pathways for those managing colorectal cancer. Each year approximately 36,000 people are diagnosed with colorectal cancer in the UK (Bowel Cancer UK, 2006) and a proportion of these will be of working age. Research in this area is important for the following reasons. Firstly, colorectal cancer affects older people (90 per cent diagnosed are over 55 years, Bowel Cancer UK, 2006) and due to falling birth rates and people living longer, Government and policymakers are encouraging people to work for longer (Centre for Research in the Older Workforce, 2004). Secondly, as well as undergoing chemotherapy / radiotherapy treatment, surgical treatment may result in life changes (e.g. stoma appliance), which in turn may impact colorectal cancer patients’ work ability. Thirdly, few studies have considered key psychosocial factors that may impact upon work ability for colorectal cancer (e.g. self-efficacy, social support and treatment). Although self-efficacy and social support have been considered as important factors in patients’ management of their cancer diagnosis and treatment, the impact of these two factors on work ability have scarcely been considered. This is somewhat surprising as findings from cancer adjustment studies suggest self-efficacy is an important factor (Cunningham et al., 1991) and therefore its role should be considered in the return to work and work ability of those recovering from cancer.

This study therefore offers a novel insight into the work ability of newly diagnosed colorectal cancer patients. The research study took approximately six months to complete and utilised both quantitative and qualitative methods; this helped to gain a holistic and coherent understanding of cancer and work
ability a combined quantitative and qualitative approach was chosen. According to some, to understand such experiences “requires a broad range of perspectives and skills” (Casebeer & Verhoef, 1997, p. 1).

Indeed, it is acknowledged that the two paradigms are characteristically different, particularly in terms of their associated philosophical assumptions (Lincoln & Guba, 1985). The quantitative paradigm relates to the notion of “an objective reality that exists independent of human perception” (Sale, Lohfeld & Brazil, 2002, p. 44). By contrast, the qualitative paradigm is concerned with realism, interpretive and constructionist thus focusing on process and meanings (Secker, Wimbush, Watson & Milburn 1995; Guba & Lincoln, 1994; Sale et al., 2002). Such inherent differences have formed the basis of arguments suggesting that using these methods in tandem would be inappropriate (Lincoln & Guba, 1985). However, others refute this argument (Casebeer & Verhoef, 1997; Steckler et al., 1992; Clarke & Yaros, 1998). For instance, the argument posited by Clarke and Yaros (1988) as cited in Sale et al. (2002) is relevant to this thesis, whereby, “combining research methods is useful in some areas of research...because the complexities of phenomena requires data from a large number of the perspectives” (p. 46).

In short, this thesis utilised a mixed methodological approach encompassing both quantitative and qualitative elements to address the research objectives and aims. Quantitative methods sought to measure the cancer and work experience; whereas qualitative methods were used to gain an understanding into the nature and meaning of the experience (Sale et al., 2002). Therefore, the resulting research objective and aims were to:

1. **Examine the employment and psychosocial well-being outcomes of colorectal cancer patients over a longitudinal period in the UK.**

Firstly, using survey data, this study assessed the employment outcomes of colorectal cancer patients over a period of time. Research discussed earlier during this chapter highlighted the importance of variables such as age, treatment and psychosocial well-being. With regard to age, research indicates that older patients were less likely to return to work (Bouknight et al., 2006).
Lima et al. (1997) found for those aged 50 years or less return to work was 74 per cent. However, for those over the age of 50 years return to work was 30 per cent. In a sample of various cancer types, Taskila et al. (2007) found older age to be associated with lower work ability. However, other research indicates that age does not impact work ability (de Boer et al., 2008) or return to work outcomes (Johnsson et al., 2007). Furthermore, when considering treatment, evidence suggests absence was significantly higher in early-stage breast cancer patients that underwent chemotherapy or multimodal treatment (Balak et al., 2008). Johnsson et al. (2007) found chemotherapy was significantly associated with return to work in breast cancer patients. Such findings have been supported in patients with prostate and breast cancer (Bradley et al., 2006). Moreover, de Boer et al. (2008) reports low work ability scores in those receiving chemotherapy. Research investigating the role of cancer diagnosis and treatment on work ability is still in its early stages particularly for colorectal cancer patients; therefore, this study provides an insight into this group. The hypotheses to be examined in relation to this objective were as follows and the results of this study are presented and discussed in Chapter 4:

**Hypothesis i)** Levels of fatigue, depression, quality of life and self-efficacy (psychosocial well-being) will vary over time; furthermore, when compared with individuals receiving chemotherapy or a combination of treatments those receiving surgery alone will show the most pronounced improvements.

**Hypothesis ii)** Levels of perceived work ability will vary over time; furthermore, when compared with individuals receiving chemotherapy or a combination of treatments those receiving surgery alone will show the most pronounced improvements.

2. To consider the role of self-efficacy and psychosocial well-being on work ability and employment outcomes.

Studying self-efficacy in relation to cancer patients’ well-being, work ability and return to work intentions is important as self-efficacy has been argued to play a pivotal role in a variety of health and work-related areas; therefore, indicating it may be of importance here. However, little is known about the mechanisms in which self-efficacy may have an effect upon work outcomes of cancer patients.
that are employed at diagnosis. On the most basic level self-efficacy could operate as a mechanism within the individual that may determine how the person perceives their work ability and what their return to work intentions may be; alternatively, these relationships may be more complex. Firstly, a patient’s work self-efficacy and cancer-specific self-efficacy may differ. Whilst patients may feel that they are able to confidently self-manage their cancer, they may not express the same self-belief in their work ability. Hence, this highlights the need to assess these domains of self-efficacy separately, which to the researcher’s knowledge has not been carried out previously.

Secondly, differing self-efficacy levels may be related to various psychosocial and work-related factors. For instance, a cancer patient who works in a physically demanding job may not feel able to perform (poor work ability) in the manner prior to the cancer (Spelten et al., 2002). Thus, the individual could be on sick leave for longer or withdraw from work altogether (retire or find something new). Psychosocial and physical well-being such as the experience of fatigue, depressive symptoms and altered bowel habits in this group may also negatively impact self-efficacy beliefs. A lack of social support (e.g. from employer) may further exacerbate this impact which overall could result in poorer self-assessed work ability and employment outcomes. Considering the nature of these variables and their relationships with work ability and employment status over time is necessary. The following set of hypotheses was therefore addressed utilising a longitudinal (quantitative) questionnaire for which the findings are presented and discussed in Chapter 5:

**Hypothesis iii)** Cancer self-efficacy and job self-efficacy may be inherently different.

**Hypothesis iv)** Levels of self-efficacy and psychosocial well-being will be associated with perceived work ability (cross-sectional and longitudinal).

**Hypothesis v)** Levels of self-efficacy, psychosocial well-being and work ability will be associated with employment status (cross-sectional and longitudinal).
In addition to the research objectives outlined previously, a number of research aims were derived and addressed using a qualitative approach:

3. To understand the temporal fluctuations and patterns in cancer management, return to work intentions and work ability.

3i) To understand the temporal nature of self-efficacy beliefs and how such beliefs may impact upon self-management and subsequent return to work intentions and perceptions of work ability.

3ii) To consider the level and nature of social support received and whether this may benefit individuals’ self-efficacy beliefs and subsequent self-management and work outcomes.

As self-efficacy has not been studied in great detail in this research area, this study utilised a qualitative diary to explore the temporal nature of this variable (research aims 3i and 3ii). This allowed the researcher to provide a multi-faceted insight into the possible role of self-efficacy in the experience of cancer and how it may impact work ability and return to work intentions over time. Research reported in the generic cancer and psychosocial well being literature suggests levels of self-efficacy are important in understanding adjustment and quality of life (Arora et al., 2002; Lev et al., 2001). Essentially, an individual’s working life could be viewed as a key quality of life outcome; thus, the role self-efficacy is likely to be multi-faceted and of relevance when considering cancer patients’ employment outcomes. Furthermore, little is known about the extent to which self-efficacy beliefs may fluctuate over time, over the cancer pathway (e.g. diagnosis and treatment) and how such beliefs may impact work ability and return to work intentions within the context of the cancer experience. Additionally, Chapter 1 discussed the beneficial value of social support in relation to cancer self-management. Therefore, considering this along with self-efficacy beliefs was an additional aim. Chapter 6 therefore presents the findings from this study and addresses these aims.
4. To explore the nature and extent to which work-related advice is provided to colorectal cancer patients by health care professionals.

4i) To understand the nature and type of information currently provided to working-aged cancer patients and the impact this may have on patients.

4ii) To identify factors that may influence the type of information given.

The nature of the patient and health professional relationship during cancer diagnosis and treatment is important. Health professionals provide information to cancer patients on diagnosis, treatment and prognosis. Although the potential effects of different types of treatments are discussed with patients, not enough is known about the extent to which disease and treatment(s) effects upon work capacity are discussed with working-aged patients (Maunsell et al., 1999; Verbeek, 2006). According to some studies, the role of health professionals (e.g. doctors) is pivotal in helping patients re-enter the work place after a cancer diagnosis (Verbeek, 2006). In a qualitative study with breast cancer patients, Maunsell et al. (1999) reported that these issues were rarely discussed. Moreover, results suggested that these women assumed it would be difficult to work during treatment, hence, considered it normal to stop during this time (Maunsell et al., 1999). Research by Verbeek, Sprangers, Kammeijer and Sprangers (2003) also found that only half of the cancer survivors in the sample had discussed return to work with their physician. More recently, in an interview study, Kennedy et al. (2007) reported that some participants stated that work matters were not discussed with their doctor. Surprisingly, these individuals were unsure whether their doctor knew about their work status. For the few that did discuss work matters, it was reported that work decisions were ultimately left up to them. Maunsell et al. (1999) argued that this lack of discussion may exacerbate concerns and apprehensions cancer patients and survivors may have about resuming work.

Therefore, research is needed to examine why health professionals may not be providing guidance in this area. Firstly, there are already high demands placed upon health professionals, which are indicative in the high levels of stress and
burnout observed in these groups (e.g. colorectal surgical consultants) (Sharma, Sharp, Walker & Monson, 2008). Secondly, the proposed short ten minute consultation times inevitably lead to the consultation focussing largely on disease and treatment factors. However, Verbeek et al. (2003) suggest that with continuity of care, more specific guidance (e.g. work-related) could be possible. Whether this is within the realm of consultants and specialist nurses requires further study. Finally, the present lack of specific guidance may also be explained in part by the notion that consultants and specialist nurses are unaware of what their role in the return to work process should be (Aitken & Cornes, 1990). Consequently, Chapter 7 explores the type and nature of work-related guidance currently provided to patients in the UK. This, along with findings from the survey and diary studies may enable common patterns to be seen and help to identify subsequent improvements that could be made to this aspect of patient care.
Chapter 3

3. **Methodology**

3.1. **Design**

The study was a longitudinal design where data were collected from participants over a six month period. A combined quantitative and qualitative methodology was utilised consisting of survey questionnaires and a qualitative diary that were completed by colorectal cancer patients. This thesis therefore presents data based upon three different but interlinked studies: a longitudinal survey; a qualitative diary, and an interview study comprised of health professionals. This mixed-method approach has three benefits: different methods or tools are suited to different tasks; both are necessary in order to answer complex and new questions and combining approaches aims to result in a synergistic effect due to the interaction of both approaches (De Vries et al, 1992) and also enables feedback between assumptions and data, thereby, enhancing the validity of results. The methodology that is presented within this chapter relates to the longitudinal survey study. Detailed information regarding the diary study and the health professionals' interview study are discussed in their corresponding chapters (6 and 7). For the quantitative survey element, participants were assessed at three time points. Time point one assessment provided baseline data and were collected when participants were recruited. To monitor any changes in health, general well-being, work ability and employment outcomes, data were collected approximately three (follow-up time 1) and six months (follow-up time 2) after baseline.

3.2. **Recruitment and Ethical Approval**

The process of gaining access to colorectal cancer patients and obtaining ethical approval took approximately a year.
Recruitment

The recruitment process comprised of two approaches where participants were recruited from either an NHS (National Health Service) Trust or an online support group affiliated to a UK based cancer charity (Macmillan / Cancerbackup) that have cancer specialist nurses attached to them. In terms of gaining access to patients through NHS Trusts, the researcher identified and approached consultant surgeons (colorectal) and oncologists working within hospitals in the Midlands area. These health professionals were provided with information about the study and what it involved. Three consultants, each from a different NHS Trust, expressed an interest in collaborating. Subsequently, the researcher was successful in gaining access to patients at three NHS Trusts.

Ethical Approval

After receiving support from the three consultants, the researcher obtained ethical approval from a local NHS Research Ethics Committee (Nottingham REC 2) and the appropriate Research and Development departments affiliated to each NHS Trust. Ethical approval was also obtained from Loughborough University’s Advisory Committee (Appendix 2, approval letters).

3.2.1. Participants

Participants were recruited from either three acute NHS Trusts ($n = 27$) across the Midlands or an online support group ($n = 23$). Fifty colorectal cancer patients participated in the longitudinal survey (male; $n = 28$). In addition, a sub-sample of ten participants (female; $n = 7$), completed the monthly diary study (see Chapter 6, p. 126). Survey participants were aged between 40 and 63 years with a mean age of 52.49 years ($SD = 5.42$). Those meeting the study inclusion criteria were invited to participate by their consultant or cancer nurse, who referred them to the researcher, or by responding to the online post submitted by the researcher. The inclusion criteria were: (a) employed at time of diagnosis ($\geq 18.5$ hours per week); (b) be diagnosed with primary colorectal cancer; (c) be able to speak, write and read English, and (d) have a permanent address or contact details. Invitation letters (Appendix 3) and participant information sheets (Appendix 4) detailing the research were provided to those
expressing an interest. Those meeting the inclusion criteria and wishing to participate were asked to complete an informed consent form (Appendix 5).

3.3. Power Calculation: Sample Size

All but two of the hypotheses were to be tested using regression models. Calculating power for regression models required prior knowledge from existing studies on outcome and predictor variables which is limited in terms of this study’s population. Thus, the researcher used the information that was available during the early planning stages (October 2006) in the best way possible to estimate power of the models. The desired sample size was calculated based upon a mean return to work rate of 62% that was obtained from a review of 14 studies that examined return to work in different cancer populations (Spelten et al., 2002). This was chosen as it was the most comprehensive relevant data that was available (at the time) on return to work in cancer patients. All calculations were carried out using Power and Precision software (Borenstein, Rothstein & Cohen, 2001). Hence, for a regression model where all significance tests were to be performed at $\alpha = 0.05$ for two-tailed tests and $\beta = 0.80$ (power), the researcher required 85 participants to detect a 19% increase in return to work related to one standard deviation increase in self-efficacy score including a second continuous predictor variable of depression$^1$. This model assumed correlation between predictor variables to equal $r = -0.30$ and an odds ratio (OR) of 2.31 for self-efficacy (based on a 1 SD change in the self efficacy score) and an OR of 0.50 (based on a 1 SD change in depression score) for depression. This moderate correlation between these predictor variables has been reported in persons with asthma (Mancuso, Melina, McCulloch & Charlson, 2001).

$^1$ Prior self-efficacy (Lam & Fielding, 2007) and depression (Kornblith et al., 2007) means/standard deviations were selected from existing research utilising cancer populations.
3.4. Measures

Data collection comprised of three measures: 1) Background Questionnaire (Appendix 6); 2) Managing Cancer and Employment Questionnaire (Appendix 7), and 3) Diary (Appendix 8). Hence, these included both quantitative and qualitative elements. These are outlined below:

3.4.1. Background Questionnaire

*Demographics*

Information was collected on: participants’ age (date of birth) and ethnicity, which was assessed by utilising a Government designed measure (Sustainable Development Commission, 2005). Education was assessed with one item that asked participants to disclose the highest qualification that they held. Three items sought to gather information about participants’ occupation (current employment status, type of employment [manual / non manual] and tenure).

*Illness*

Six items were developed to gather information regarding the illness (diagnosis) and illness severity (stage if known). Participants were asked to indicate the treatment(s) they were receiving and any treatment(s) they had completed (surgery, chemotherapy, radiotherapy and / or other). Prior experiences of cancer were noted, along with any additional chronic illnesses.

3.4.2. Cancer and Employment Questionnaire

This section describes the measures that were used to assess psychosocial and work factors at each time point (baseline, follow-up time 1 and follow-up time 2) and are summarised in Table 3.1. The Managing Cancer and Employment Questionnaire (Appendix 7) comprised of three sections: Section A was to be completed by all participants; Section B was to be completed by those who were working at the time of questionnaire completion, and Section C was completed by those who had stopped working, or were on sick leave. The measures contained within each section are described below:
Table 3.1: Scales administered at each time point.

<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
<th>Follow-up Time 1</th>
<th>Follow-up Time 2</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>All participants</strong></td>
<td>Background Questionnaire (socio-demographics and disease-specific information)</td>
<td>Beck Depression Inventory</td>
<td>Beck Depression Inventory</td>
</tr>
<tr>
<td></td>
<td>Fatigue Severity Scale</td>
<td>Chronic Disease Self-Efficacy Scale</td>
<td>Chronic Disease Self-Efficacy Scale</td>
</tr>
<tr>
<td></td>
<td>Chronic Disease Self-Efficacy Scale</td>
<td>Functional Assessment of Cancer Therapy</td>
<td>Functional Assessment of Cancer Therapy</td>
</tr>
<tr>
<td></td>
<td>Fatigue Severity Scale</td>
<td>Scale</td>
<td>Therapy Scale</td>
</tr>
<tr>
<td></td>
<td>Functional Assessment of Cancer Therapy</td>
<td>Job Self-Efficacy</td>
<td>Job Self-Efficacy</td>
</tr>
<tr>
<td></td>
<td>Scale</td>
<td>Work Ability Index</td>
<td>Work Ability Index</td>
</tr>
<tr>
<td></td>
<td>Job Self-Efficacy</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Work Ability Index</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Section A

Depression

The Beck Depression Inventory (BDI-II; Beck, Steer, & Brown, 1996) was utilised to measure the intensity of depressive symptoms in participants. This is one of the most frequently used depression scales and has demonstrated good validity and reliability (Kline, 2000). In the cancer population, studies using this measure have also reported high reliability (Pinquart et al., 2006). The inventory comprises of 21 statements where participants were asked to select the one that best described the way they have felt during the past 2 weeks. Items assessed depressive symptoms such as hopelessness and irritability, cognitions such as guilt and physical symptoms such as fatigue and weight loss. For example, of the following four statements, participants had to choose the one statement that they most agreed with: ‘I do not feel sad’, ‘I feel sad’, ‘I am sad all the time’, or ‘I am so sad or unhappy that I can’t stand it.’ Items are scored on a four-point scale (0 – 3); scores are summed and range from zero to sixty-three. Higher scores denoted more severe depression. A score >20 is usually considered indicative of clinical depression, while a score of ≤10 is non-depressed. Finally a boundary for mild depression is ten. Internal consistency of the scale for each time point was $\alpha = 0.86; 0.88; 0.85$ respectively.

Fatigue

The Fatigue Severity Scale was used to assess fatigue (Krupp et al., 1989). It is a nine item scale developed for measuring fatigue in patients with chronic illness. The scale has been utilised with cancer patients and has demonstrated good reliability and validity (Stone, Richards, A’Hern, & Hardy, 2000). Agreement with statements such as, ‘fatigue interferes with my physical functioning,’ are ranked on a seven-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree). The test score is averaged to provide a score ranging from 1 - 9. A score of 5.5 has previously been used as an indicator of fatigue (Lichstein, Means, Noe, & Aguillard, 1997). The scale had an internal consistency of $\alpha = 0.89$ at baseline; $\alpha = 0.94$ at follow-up time 1 and follow-up time 2.
Quality of Life

The Functional Assessment of Cancer Therapy Scale (FACT-G) was utilised to assess quality of life (Cella et al., 1993). The scale comprised of 26 items that assessed quality of life in cancer patients undergoing treatment. The scale has been validated utilising 854 cancer patients (Cella et al., 1993). The scale asked participants to rate how true statements such as, ‘I am satisfied with how I am coping with my illness’, were on a five-point Likert scale from 0 (not at all true) to 4 (very much true). Responses to the 26 items were combined into four quality of life scales: physical well-being (7 items); social/family well-being (6 items); emotional well-being (6 items); functional well-being (7 items). A total score was calculated to indicate overall quality of life, where a higher score indicated more positive quality of life. The scale had a good internal consistency across all three time points, with Cronbach alpha coefficients reported of 0.89 (baseline), 0.92 (follow-up time 1) and 0.91 (follow-up time 2).

Self-Efficacy

Cancer self-efficacy was assessed utilising 14 items taken from the Chronic Disease Self-Efficacy scales (Lorig et al., 1996). The scale asked participants to rate how confident they were in performing certain activities such as, ‘do all the things necessary to manage your condition on a regular basis’, on a ten-point Likert scale ranging from 1 (not at all confident) to 10 (totally confident). Four sub-scales were utilised: communicate with physician (3 items); manage disease in general (5 items); manage symptoms (5 items), and one item that assessed confidence in getting information about the disease. A total cancer self-efficacy score was calculated, where a higher score indicated higher cancer self-efficacy. The scale demonstrated good internal consistency (α = 0.76 baseline; α = 0.93 follow-up time 1; α = 0.93 follow-up time 2).

Work Ability

Work ability was assessed using three items taken from the Work Ability Index (Tuomi et al., 1998). This method has been adopted by previous researchers (e.g. de Boer et al., 2008). For example, participants were presented with the following item and were asked to rate their current work ability on a ten-point
Likert scale ranging from 0 (cannot work at all) to 10 (work ability at best) ‘assume that your work ability at its best has a value of 10 points. How many points would you give your current work ability?’ Internal consistency of the scale was calculated for each time point; however, these should be treated with caution as a small number of items were utilised from the original scale ($\alpha = 0.58; \alpha = 0.59; \alpha = 0.56$).

**Job Self-Efficacy**

Job self-efficacy was assessed by modifying a return to work self-efficacy scale used in patients with back pain (Shaw & Huang, 2005). The scale comprised of 18 items which asked participants to rate how confident they were in performing certain activities at work, or if they were at work on a ten-point Likert scale ranging from 1 (not at all confident) to 10 (totally confident). For example, ‘how confident are you that you can suggest to your supervisor ways to change your work to reduce discomfort?’ A total score was calculated to indicate job self-efficacy with higher scores indicating higher levels of job self-efficacy. The scale demonstrated respectable internal consistency across all three time points ($\alpha = 0.90; \alpha = 0.95; \alpha = 0.91$).

**Section B**

**Disclosure**

Disclosure of illness was measured with two items. Participants were asked to indicate (Yes / No) whether they had disclosed their illness to their line manager or employer and colleagues.

**Section C**

**Sick-leave and Not working**

Eleven items were included for those who were on sick-leave (when questionnaire was completed), or who had withdrawn from the workplace altogether. These items assessed when participants left work, reasons for this and whether they intended to return to work in the future. Items also asked whether participants had disclosed their illness to colleagues and managers.
3.4.3. Qualitative Data: Diary

To gather more in-depth and rich information about the role of self-efficacy in the management of cancer and work, participants were offered the opportunity to complete a diary booklet (Appendix 8). Of the 50 participants that completed the survey data, 10 took part in the diary study. The diary was designed to capture the more subtle, temporal fluctuations in perceptions of self-efficacy and the factors (illness self-management) that impacted upon these. Therefore, it served to supplement the data captured by the questionnaires. Please refer to Chapter 6 (pp. 123-179) which discusses this study, its associated methods and results in detail.

3.4.4. Health Professionals’ Interview Study

The final study recruited a sample of 18 health professionals from a number of fields. These individuals participated in a semi-structured interview to explore the extent to which they provided work-related advice and guidance to cancer patients. The aims, methods and results of this study are presented in Chapter 7 (pp. 180-209).

3.5. Procedure

Those meeting the study inclusion criteria were provided with an invitation letter (Appendix 3) and participant information sheet (Appendix 4) by their consultant, cancer nurse or the researcher (see Figure 3.1). Consequently, potential participants were briefed in writing and / or verbally. Those wishing to participate were required to complete the informed consent form. Upon completion of the consent forms the researcher informed participants that they were NOT a clinician or cancer nurse. Moreover, participants were informed that their clinician and cancer nurse would be notified of their participation. Participants were advised to contact any of these persons and / or Cancerbackup if they felt distressed during any point of the study duration. The researcher explained that all sensitive data would be kept strictly confidential and that they would only be identifiable to the researcher by a unique code assigned to them at the start of the study. Participants were made aware (via information sheet, consent form and verbally) that they could withdraw from the
study at any point without any consequences, particularly in relation to their
treatment and / or standard of care. Participants were then provided with the
study documents.

3.5.1. Questionnaire Administration

It is important to mention that participants recruited from the support group were
given the option to complete the questionnaire by post or online (via Survey
Monkey). All participants were administered two questionnaires once they had
been recruited. This provided baseline data (time point one). The first
questionnaire (Background Questionnaire, Appendix 6) assessed socio-
demographic and illness variables and took no longer than 15 minutes to
complete. The second questionnaire (Managing Cancer and Employment,
Appendix 7) was provided to monitor the effects of colorectal cancer, treatment,
psychological, social and work factors on ability to work. This questionnaire
took approximately 30 minutes to complete. The researcher advised
participants to complete the questionnaires at home. Each participant was
provided with a stamped addressed envelope to return completed
questionnaires to the researcher.
Recruitment
Process (varied at each
NHS Trust and support
group)

Briefing Session

Assessment 1
(Baseline)

Assessments 2&3
(3 & 6 months after
assessment 1)

Recruitment letter/
Information Sheet

1. Principal Investigator visits
clinic-patients referred
2. Support group contact
researcher.

Information Sheet

Consent form

Background Questionnaire

Colorectal Cancer Patients

Managing Cancer &
Employment Questionnaire

Diary (Optional)

Managing Cancer &
Employment Questionnaire

Figure 3.1: Diagram of Protocol
The Managing Cancer and Employment Questionnaires were sent to participants at time points two (follow-up time 1; approximately 3 months after baseline) and three (follow-up time 2; six months after baseline). This enabled the researcher to monitor any changes in health and work ability and to map employment behaviours in participants. It enabled more accurate information to be collected on when participants decided to take sick leave, returned to work and/or exit employment and what psychosocial and/or work-related factors were most likely to influence these decisions. Participants were asked to complete and return the questionnaires in a stamped-addressed envelope within a week of when they were received. The researcher retrieved questionnaires completed online and printed a paper copy to store in separate participant files.

3.5.2. Ethical Considerations

All personal data obtained were kept under conditions of strict confidentiality as required by the law in the Data Protection Act 1998. Data were only accessible to the researcher and research supervisors. However, in order to monitor data collated at each time point, participants were allocated a unique code that was used as an identifier on study measures. All personal data linking participants to a code were maintained on a database that was kept separately from other study documentation. Personal data and research data were kept on a secure password-protected university computer that was only accessible to the researcher.

3.6. Data Analysis

As an initial step, data cleaning procedures were undertaken to ensure that there were no errors inherent (e.g. checked frequencies) and that data were normally distributed. An independent-samples t-test was conducted to compare baseline age, fatigue, depression, quality of life, self-efficacy and work ability scores for NHS participants and support group participants; no significant differences between the groups were detected \( (p > 0.05) \). Subsequently, data obtained from the survey assessments were analysed using both analysis of variance and hierarchical regression models. Analysis of variance techniques
were utilised to consider the stability of psychosocial well-being and work variables over the study period. Furthermore, differences in self-assessed work ability were considered according to treatment type. Finally, both cross-sectional and longitudinal hierarchical regressions models were tested to consider variables related to both work ability and employment status over time. Further details regarding data analysis for each study (particularly qualitative studies) are provided in their corresponding chapters.
Chapter 4

4. The Impact of Colorectal Cancer on Psychosocial Well-Being and Work Ability

4.1. Introduction

The aim of this chapter is to consider the impact of time and cancer treatment type upon measures of psychosocial well-being and work ability. Numerous studies indicate that the physical and psychosocial impacts of cancer and its treatment are plentiful. Evidence suggests many cancer patients experience a range of psychosocial outcomes including fatigue, depression and poorer quality of life outcomes as a result of their cancer diagnosis, treatment and recovery (Spelten et al., 2003; Short et al., 2005; Pasquini et al., 2006). Furthermore, these symptoms are likely to fluctuate over time; for instance, fatigue is more pronounced in patients undergoing more than one treatment modality or chemotherapy (de Boer et al., 2008; Bradley et al., 2007). It is important to understand the stability of such psychosocial impacts as they are likely to have implications on work ability, return to work intentions and employment outcomes. Evidence suggests that the more side effects or symptoms experienced can exacerbate detrimental effects on work ability and work outcomes (Spelten et al., 2002; Taskila & Lindbohm, 2007).

Therefore, this chapter examines the impact of colorectal cancer on psychosocial well-being and work ability over a six month period. Participants completed three questionnaires during this time, at baseline (diagnosis), follow-up time 1 (3 months later), and follow-up time 2 (6 months later) that allowed changes in psychosocial outcomes to be identified, these included: fatigue, depression, quality of life, self-efficacy and work ability. Furthermore, differences according to treatment type were also examined whereby patients receiving surgery alone were compared with those receiving chemotherapy; or chemotherapy plus surgery; or radiotherapy plus surgery, or chemotherapy plus surgery and radiotherapy. The hypotheses explored were as follows:
Hypothesis i) Levels of fatigue, depression, quality of life and self-efficacy (psychosocial well-being) will vary over time; furthermore, when compared with individuals receiving chemotherapy or a combination of treatments those receiving surgery alone will show the most pronounced improvements.

Hypothesis ii) Levels of perceived work ability will vary over time; furthermore, when compared with individuals receiving chemotherapy or a combination of treatments those receiving surgery alone will show the most pronounced improvements.

4.2. Statistical Analysis

The psychosocial and work measures assessed at baseline, follow-up time 1 and follow-up time 2 were analysed to examine stability over time. As an initial step, a multivariate analysis of variance (MANOVA) with time as the fixed factor was conducted where all the dependent variables (measures) were analysed together. This served to control for the Type 1 error rate. Subsequently, a series of 2 x 3 mixed analyses of variance (ANOVA) were performed if the multivariate test was significant (\( p < 0.05 \)).

Preliminary analyses revealed that there was not a significant effect of age or occupation upon the measures of well being and self-assessed work ability; therefore, these were not adjusted for in further analyses. However, differences were found according to treatment type where those who received surgery alone were compared with those who received chemotherapy; or chemotherapy plus surgery; or radiotherapy plus surgery, or chemotherapy plus surgery and radiotherapy. As a result treatment type was entered as a between subjects factor in all repeated measures ANOVAs.

4.3. Results

Participant Characteristics

Participant socio-demographics and cancer-related characteristics are presented in Table 4.1. The mean age of participants was 52.49 years (SD = 5.42; range 40 – 63 years) and 28 (56%) were male. The majority of the
participants were ‘White British’ (90%). Fourteen (28%) were employed in manual labour jobs. With regard to treatment, 15 had undergone surgery alone, 35 were being treated with one of the following treatment combinations; chemotherapy; or chemotherapy plus surgery; or radiotherapy plus surgery, or chemotherapy plus surgery and radiotherapy. Fourteen participants had a stoma appliance. When considering employment status over the study duration: 38 (76%) were on sick leave at baseline; 39 (79%) were on sick leave at follow-up time 1, and 30 (61%) were on sick leave at follow-up time 2.

**Manova Results**

A one-way within subjects MANOVA was performed on six dependent variables: fatigue, depression, quality of life, cancer self-efficacy, job self-efficacy and work ability. The independent variable was time (baseline, follow-
up time 1, follow-up time 2). Total N of 50 was reduced to 49 with a deletion of a case missing scores at follow-up times 1 and 2. Results of evaluation of assumptions of normality, linearity, homogeneity of variance-covariance matrices and multicollinearity were satisfactory. There was a statistically significant difference between time points on the combined dependent variables, \( F(12, 280) = 2.40, p = 0.006 \); Wilks' Lambda = 0.82; partial eta squared = 0.09. Regarding the predictor variables, fatigue, quality of life, cancer self-efficacy, job self-efficacy and work ability were significant (p < 0.05).

4.3.1. The Effect of Time and Treatment upon Psychosocial Well-Being

Hypothesis i) Levels of fatigue, depression, quality of life and self-efficacy (psychosocial well-being) will vary over time; furthermore, when compared with individuals receiving chemotherapy or a combination of treatments those receiving surgery alone will show the most pronounced improvements.

As an initial step, hypothesis (i) was tested to consider the longitudinal stability of psychosocial well-being of the colorectal cancer sample; furthermore, this allowed results to be compared with findings already reported in the general cancer literature. Repeated measures analysis of variance (2 x 3 mixed ANOVAs) with treatment type as a between subjects factor was conducted to assess the impact of time and treatment type on participants' scores on measures of fatigue, depression, quality of life, cancer self-efficacy and job self-efficacy, across three time points (baseline; follow-up time 1; follow-up time 2). Results are presented in relation to each measure. To consider significant findings post-hoc, the Bonferroni correction was applied to adjust for multiple comparisons.

**Fatigue**

A mixed 2 x 3 ANOVA was conducted to assess the impact of treatment type upon participants' fatigue severity, across three time points. As shown in Table 4.2, a significant interaction between treatment type and time was not found \( F(1.45, 68.16) = 0.88, p = 0.39 \), partial eta squared = 0.02. Although this was not significant, Figure 4.1 does however show that when compared with baseline, both groups appeared to experience increased symptoms of fatigue at
follow-up time 1. Furthermore, there was a significant main effect for time, $F(1.45, 68.16) = 7.42$, $p = 0.003$, partial eta squared = 0.14, with a significant decline in fatigue severity between follow-up time 1 ($M = 4.57; SD = 1.32$) and follow-up time 2 ($M = 3.95; SD = 1.37$).

Figure 4.1: Mean scores over time with fatigue as the dependent variable in a repeated measures ANOVA, with ‘treatment type’ as between group factor and ‘time’ as within factor. Lines represent standard deviation.
### Table 4.2: Mean, standard deviation and ANOVA results for repeated measures with ‘treatment type’ as between groups factor and ‘time’ as within factor.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Baseline</th>
<th>T1</th>
<th>T2</th>
<th>Effect</th>
<th>F</th>
<th>p</th>
<th>Effect Size</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue†</td>
<td>4.08</td>
<td>1.09</td>
<td>4.57</td>
<td>1.32</td>
<td>3.95</td>
<td>1.37</td>
<td>Time</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>7.42</td>
</tr>
<tr>
<td>Surgery</td>
<td>3.63</td>
<td>0.91</td>
<td>3.89</td>
<td>1.40</td>
<td>3.20</td>
<td>1.40</td>
<td>Time x Treatment</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.88</td>
</tr>
<tr>
<td>Other</td>
<td>4.28</td>
<td>1.11</td>
<td>4.87</td>
<td>1.18</td>
<td>4.28</td>
<td>1.23</td>
<td></td>
</tr>
<tr>
<td>BDI†</td>
<td>10.22</td>
<td>5.79</td>
<td>9.51</td>
<td>5.93</td>
<td>7.73</td>
<td>5.02</td>
<td>Time</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3.96</td>
</tr>
<tr>
<td>Surgery</td>
<td>8.73</td>
<td>4.69</td>
<td>7.53</td>
<td>5.84</td>
<td>7.60</td>
<td>6.12</td>
<td>Time x Treatment</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1.67</td>
</tr>
<tr>
<td>Other</td>
<td>10.88</td>
<td>6.16</td>
<td>10.38</td>
<td>5.84</td>
<td>7.79</td>
<td>4.57</td>
<td></td>
</tr>
<tr>
<td>QOL</td>
<td>67.22</td>
<td>11.53</td>
<td>70.18</td>
<td>12.75</td>
<td>76.06</td>
<td>11.33</td>
<td>Time</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>20.44</td>
</tr>
<tr>
<td>Surgery</td>
<td>66.20</td>
<td>11.43</td>
<td>74.40</td>
<td>14.82</td>
<td>80.67</td>
<td>10.36</td>
<td>Time x Treatment</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3.84</td>
</tr>
<tr>
<td>Other</td>
<td>67.68</td>
<td>11.71</td>
<td>68.32</td>
<td>11.47</td>
<td>74.03</td>
<td>11.29</td>
<td></td>
</tr>
<tr>
<td>CSE†</td>
<td>6.86</td>
<td>1.75</td>
<td>7.37</td>
<td>1.29</td>
<td>7.85</td>
<td>1.05</td>
<td>Time</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>14.70</td>
</tr>
<tr>
<td>Surgery</td>
<td>6.84</td>
<td>1.61</td>
<td>7.74</td>
<td>1.15</td>
<td>7.98</td>
<td>1.05</td>
<td>Time x Treatment</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1.02</td>
</tr>
<tr>
<td>Other</td>
<td>6.87</td>
<td>1.83</td>
<td>7.22</td>
<td>1.32</td>
<td>7.80</td>
<td>1.07</td>
<td></td>
</tr>
<tr>
<td>JSE</td>
<td>6.44</td>
<td>1.98</td>
<td>6.49</td>
<td>1.78</td>
<td>7.49</td>
<td>1.17</td>
<td>Time</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>10.85</td>
</tr>
<tr>
<td>Surgery</td>
<td>6.26</td>
<td>1.75</td>
<td>6.90</td>
<td>1.83</td>
<td>7.64</td>
<td>1.09</td>
<td>Time x Treatment</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1.32</td>
</tr>
<tr>
<td>Other</td>
<td>6.51</td>
<td>2.10</td>
<td>6.30</td>
<td>1.75</td>
<td>7.42</td>
<td>1.21</td>
<td></td>
</tr>
</tbody>
</table>

† Sphericity not assumed; Greenhouse -Geisser reported, M Mean, SD Standard deviation, Other Chemotherapy; or chemotherapy plus surgery; or radiotherapy plus surgery; or chemotherapy plus surgery and radiotherapy; BDI Beck Depression Inventory, QOL Quality of Life, CSE Cancer Self-Efficacy, JSE Job Self-Efficacy.
Depression

To consider the stability of depressive symptoms over the 6 month data collection period, a mixed 2 x 3 ANOVA was carried out that also assessed the impact of treatment type. As shown in Table 4.2, there was no interactive effect $F (1.77, 83.34) = 1.67, p = 0.20$, partial eta squared = 0.03. In contrast, there was a substantial main effect for time, $F (1.77, 83.34) = 3.96, p = 0.02$, partial eta squared = 0.08. Figure 4.2 appears to show a gradual decline in depressive symptoms over time. However, when multiple comparisons were adjusted for by applying a Bonferroni correction, this significant difference between mean depression scores at baseline (M = 10.22; SD = 5.79) and follow-up time 2 (M = 7.73; SD = 5.02) was no longer apparent ($p = 0.06$).

![Figure 4.2: Mean (SD) scores over time with depression scores used as the dependent variable in a repeated measures ANOVA, with 'treatment type' as between group factor and 'time' as within factor. Lines represent standard deviation.](image)

Quality of Life

A repeated measures ANOVA was conducted to assess the impact of treatment type on participants’ quality of life scores, across three time points. As shown in Table 4.2 and illustrated in Figure 4.3, a significant interaction between treatment type and time was found $F (2, 94) = 3.84, p = 0.02$, partial eta squared = 0.07. There was a substantial main effect for time, $F (2, 94) = 20.44$,
\( p = 0.0005 \), partial eta squared = 0.30, with a significant improvement in quality of life outcomes across all time points (\( p < 0.001 \)). Figure 4.3 exemplifies improvements in quality of life outcomes over time for both treatment groups; furthermore, the most favourable quality of life outcomes were observed in participants that were treated with surgery alone.

![Figure 4.3: Mean (SD) scores over time with work quality of life used as the dependent variable in a repeated measures ANOVA, with ‘treatment type’ as between group factor and ‘time’ as within factor. Lines represent standard deviation.](image)

**Cancer Self-Efficacy**

At each time point, participants were asked to rate how confident they were about managing certain aspects of their cancer. The results presented in Table 4.2 show that a significant interaction between treatment type and time was not found \( F(1.30, 61.12) = 1.02, p = 0.36, \) partial eta squared = 0.02. There was a substantial main effect for time, \( F(1.02, 61.12) = 14.70, p = 0.0005, \) partial eta squared = 0.24, with a significant improvement in cancer self-efficacy levels across all time points (\( p < 0.05 \)). Figure 4.4 demonstrates that participant’ self-efficacy beliefs in relation to managing their cancer increased as more time elapsed since diagnosis.
Chapter 4  Colorectal Cancer, Psychosocial Well-Being & Work Ability

Figure 4.4: Mean (SD) scores over time with cancer self-efficacy used as the dependent variable in a repeated measures ANOVA, with ‘treatment type’ as between group factor and ‘time’ as within factor. Lines represent standard deviation.

**Job Self-Efficacy**

A 2 x 3 mixed ANOVA was conducted to assess the impact of treatment type on participants’ levels of job self-efficacy, across three time points. As shown in Table 4.2, a significant interaction between treatment type and time was not found $F(2, 94) = 1.32, p = 0.27$, partial eta squared = 0.03. Figure 4.5 illustrates that those receiving surgery alone reported improvements in job self-efficacy over the six month study period; whereas when compared with baseline scores, those receiving chemotherapy, or a combination of treatment (i.e. other than surgery alone) appeared to show a decrement in job self-efficacy at follow-up time 1 that subsequently increased at follow-up time 2. There was a substantial main effect for time, $F(2, 94) = 10.85, p = 0.0005$, partial eta squared = 0.19, with a significant improvement in perceptions of job self-efficacy across all time points ($p < 0.001$).
Figure 4.5: Mean (SD) scores over time with job self-efficacy used as the dependent variable in a repeated measures ANOVA, with ‘treatment type’ as between group factor and ‘time’ as within factor. Lines represent standard deviation.

4.3.2. The Effect of Time and Treatment upon Work Ability

Hypothesis ii) Levels of perceived work ability will vary over time; furthermore, when compared with individuals receiving chemotherapy or a combination of treatments those receiving surgery alone will show the most pronounced improvements.

A 2 x 3 repeated measures ANOVA was conducted to assess the impact of treatment type on participants' scores of self-assessed work ability, across three time points. As shown in Table 4.3, a significant treatment type and time interaction was found $F(2, 94) = 5.20, p = 0.007$, partial eta squared = 0.10. Figure 4.6 illustrates that those receiving surgery alone reported improvements in self-assessed work ability over the six month study period. Those receiving chemotherapy; or chemotherapy plus surgery; or radiotherapy plus surgery, or chemotherapy plus surgery and radiotherapy showed a decrement in perceived work ability at follow-up time 1 that subsequently increased at follow-up time 2. There was a significant main effect for time, $F(2, 94) = 18.83, p = 0.0005$,.
partial eta squared = 0.27, with increases in work ability between baseline and follow-up time 1 and follow-up time 2 ($p = 0.0005$).

**Table 4.3**: Mean (SD) scores of work ability across three time points with scores as dependent variable in a repeated measures ANOVA, with treatment as a between group factor and time as within factor.

<table>
<thead>
<tr>
<th>Variable</th>
<th>M</th>
<th>SD</th>
<th>M</th>
<th>SD</th>
<th>M</th>
<th>SD</th>
<th>Effect</th>
<th>F</th>
<th>$p$</th>
<th>Effect Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work Ability</td>
<td>5.08</td>
<td>2.18</td>
<td>4.98</td>
<td>2.44</td>
<td>6.22</td>
<td>2.03</td>
<td>Time</td>
<td>18.83</td>
<td>0.0005</td>
<td>0.27</td>
</tr>
<tr>
<td>Surgery</td>
<td>5.13</td>
<td>2.26</td>
<td>6.07</td>
<td>2.18</td>
<td>7.00</td>
<td>2.13</td>
<td>Time x Treatment</td>
<td>5.20</td>
<td>0.007</td>
<td>0.10</td>
</tr>
<tr>
<td>Other</td>
<td>5.06</td>
<td>2.18</td>
<td>4.50</td>
<td>2.42</td>
<td>5.88</td>
<td>1.91</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

M Mean, SD Standard Deviation, Other Chemotherapy; or chemotherapy plus surgery; or radiotherapy plus surgery, or chemotherapy plus surgery and radiotherapy.

**Figure 4.6**: Mean (SD) scores over time with work ability used as the dependent variable in a repeated measures ANOVA, with ‘treatment type’ as between group factor and ‘time’ as within factor. Lines represent standard deviation.
4.4. Discussion

In this sample of colorectal cancer patients, various temporal patterns in self-assessed work ability and psychosocial well-being were observed. Most importantly, positive temporal changes in perceptions of cancer self-efficacy and job self-efficacy were detected. These variables have scarcely been considered in prior studies comprised of cancer patients / survivors. In addition, the study provided a novel insight into colorectal cancer patients’ work ability.

Results regarding self-efficacy beliefs were promising. When considering job self-efficacy beliefs, an aspect that has not been considered previously, levels were found to improve over time. Nonetheless, an interaction between treatment type and time did not emerge. Despite this non significant statistical finding, inspection of the mean scores for both groups suggests that the pattern of self-efficacy beliefs were different according to treatment type. Participants that received surgery alone showed increments in their ability to perform their job role across time; whereas those whose treatment comprised of chemotherapy, or a combinations of treatments (more than one type) exhibited a decrease in scores between baseline and follow-up time 1 (6.51; 6.30) that subsequently improved at follow-up time 2 (7.42). This pattern of findings also emerged when considering work ability mean scores at each time point for this treatment group (5.06; 4.50; 5.88). This decrement could therefore be attributed to the onset of chemotherapy or radiotherapy treatment. In other words, at baseline (post surgery but pre chemotherapy / radiotherapy) this group were likely to be unaware of potential treatment effects; therefore, perceptions related to performing their job role may not have been negatively influenced. However, at follow-up time 1, treatment would have commenced for most; this may have meant participants had no choice but to be more realistic about what their work capabilities were. This argument regarding treatment effects is further strengthened by the findings from the group that received surgery alone who displayed improvements in both job self-efficacy and work ability across time points. An alternate argument could be posited, whereby patients' treatment regimen may have been a barrier preventing a return to work even when patients felt confident about performing their job tasks. However,
work ability scores do not appear to support this suggestion. Nevertheless, this is a matter the qualitative diary study (Chapter 6) hopes to delineate further.

Participants demonstrated increased confidence in their ability to self-manage their cancer over the six month data collection period. The potential beneficial value of high self-efficacy upon disease management has been supported in the existing chronic illness literature (Clark & Dodge, 1999; Han et al., 2003). Examination of the mean values for cancer self-efficacy at each time point (6.86; 7.37; 7.85) however suggest that participants already possessed quite reasonable self-efficacy beliefs at baseline. Based upon this, one could have expected the improvement in self-efficacy beliefs to be more pronounced at subsequent time points. Although it is difficult to ascertain the precise explanation for this, it could be explained by symptoms such as fatigue that were found to worsen at follow-up time 1 for participants that were treated with chemotherapy, or a combination of treatments; though this change was not found to be significant. In evaluation, having another time point beyond six months or upon completion of treatment may have led to more significant improvements in self-efficacy outcomes. Prior research has however reported an association between treatment type and fatigue severity that has also been found to predict return to work (Spelten et al., 2003) and work ability outcomes (Steiner et al., 2008). The findings are in line with those that have previously examined the association between self-efficacy, adjustment and quality of life outcomes. For instance, Cunningham et al. (1991) found strong positive correlations between self-efficacy and quality of life. Meanwhile, Kreitler et al. (2007) utilised structural equation modelling to find that self-efficacy had a direct effect upon quality of life outcomes. However, self-efficacy beliefs also exerted an indirect influence upon quality of life, via perceived stress. Therefore, as suggested in Chapter 1, self-efficacy is unlikely to operate as a mechanism alone. Moreover, the diary study presented in Chapter 6 aims to explore the association between self-efficacy and social support that has also been argued to be fundamental in understanding the mechanism by which self-efficacy exerts an influence (Kreitler et al., 2007).
When considering the stability of psychosocial well-being and work ability over time, these findings indicate that treatment type may be more important than cancer type when considering individuals’ employment outcomes. Furthermore, by assessing patients’ / survivors’ self-efficacy beliefs, particularly during the early stages of treatment could help towards identifying those who may require supportive strategies to enhance these beliefs. Self-efficacy enhancing strategies have been employed in breast cancer patients undergoing chemotherapy (Lev et al., 2001). This intervention led to increments in quality of life and decreased symptom distress (Lev et al., 2001). Moreover, employing these interventions at an early stage may subsequently result in better work outcomes; for example, higher self-efficacy beliefs and work ability could lead to an earlier resumption of employment.

4.5. Summary

In summary, this study adds to existing research findings by identifying changes in the self-efficacy beliefs and work ability of colorectal cancer patients. Additionally, the study successfully corroborates existing research findings that have identified that cancer patients / survivors are likely to experience changes in their psychosocial well-being over the cancer pathway. Furthermore, the association between treatment type and psychosocial outcomes in this colorectal cancer sample seems to be similar to existing research that has utilised various cancer types (e.g. Spelten et al., 2002; Tsunoda et al., 2007), whereby those receiving more than one treatment modality or chemotherapy treatment were most likely to report unfavourable outcomes. This was found to be the case for work ability and quality of life outcomes. Encouragingly, the results indicate that colorectal patients are likely to show significant improvements in both their work-related and psychosocial well-being within the six months following diagnosis. The following chapter aimed to take these findings a step further to identify whether any of these factors were significantly related to work ability and employment status.
5. Predictors of Work Ability and Employment Status: The Role of Self-Efficacy

5.1. Introduction

The potential impact of cancer and its treatment on working life is substantial with approximately 40% of all cancer patients taking time off work during treatment and recovery (Short et al., 2005). In spite of this, little is known about the work outcomes of working-aged colorectal cancer patients.

Studies have identified a number of key factors that impact upon return to work and work outcomes for those recovering from cancer. These are outlined effectively in review papers by Spelten et al. (2002) and more recently by Taskila and Lindbohm (2007). From such research, it is apparent that some of the more prominent variables associated with return to work and employment outcomes appear to be cancer type (those with head, neck, lung, leukaemia and stomach cancer less likely to return to work), treatment (more than one treatment modality or chemotherapy are less likely to return to work / take longer), age (increasing age less likely to return to work) and occupation (manual labour less favourable work outcomes) (Spelten et al., 2002; Taskila & Lindbohm, 2007).

Factors predicting work ability are also becoming more apparent (e.g. Taskila & Lindbohm, 2007; Bradley et al., 2007; Feuerstein et al., 2007; de Boer et al., 2008; Munir, Yarker, et al., 2009). To provide a more coherent account of the factors associated with work ability and employment outcomes, studies need to consider whether any additional (unacknowledged) factors pertain. To the researcher’s knowledge, the possible role of self-efficacy as a factor predicting work ability has previously not been considered in relation to employment outcomes of cancer patients or survivors. Findings from studies suggest self-efficacy is an important factor that has been found to predict psychosocial
adjustment in individuals affected by cancer (Cunningham et al., 1991). Subsequently, the aim of this study is to consider the role of self-efficacy (along with previously identified factors) in relation to the work ability and employment outcomes of working-aged colorectal cancer patients. It is acknowledged that not accounting for disease severity in the analyses is an inherent weakness as it has previously been found to be associated with return to work (Buckwalter et al., 2007) and perceived work ability (Taskila & Lindbohm, 2007); however, this information was not available for the entire sample.

The study utilised the same longitudinal survey where participants (N = 50) completed three questionnaires over a six month period: baseline, follow-up time 1 and follow-up time 2 (Chapter 3, Methodology, pp. 69-81). The hypotheses to be addressed were:

*Hypothesis iii) Cancer self-efficacy and job self-efficacy may be different.*

*Hypothesis iv) Levels of self-efficacy and psychosocial well-being will be associated with perceived work ability (cross sectional and longitudinal).*

*Hypothesis v) Levels of self-efficacy, psychosocial well-being and work ability will be associated with employment status (cross sectional and longitudinal).*

### 5.2. Statistical Analysis

All analyses were carried out using SPSS version 16.0 (SPSS, Inc., Chicago, IL). Missing data did not appear to pose a problem as only one participant withdrew from the study at follow-up time 1. The relationships between the key variables were investigated separately at each time point using Pearson product-moment correlation coefficients. Separate hierarchical regression and logistic regression analyses were conducted for data at each time point to investigate variables related to job self-efficacy, work ability and employment status at baseline, follow-up time 1 and follow-up time 2. Following this, prospective analyses were conducted where baseline scores for each dependent variable were controlled for along with other baseline psychosocial
and work-related variables to predict follow-up time 2 outcomes. This approach was adopted as it allowed variables to be entered into the model in a certain order on a theoretical basis (Brace, Kemp & Snelgar, 2006). Due to the study sample size, variables controlled for at each time point were selected based upon findings of previous research (e.g. Taskila & Lindbohm, 2007; de Boer et al., 2008) with the most prominent ones being entered into the models. Therefore, age, occupation and treatment type were included as covariates in all the work ability and employment status analyses. Occupation was dichotomized (0 = manual; 1 = non manual) and treatment type was dummy-coded; whereby surgery was compared against all other combinations of treatment (0 = surgery; 1 = chemotherapy; or chemotherapy plus surgery; or radiotherapy plus surgery, or chemotherapy plus surgery and radiotherapy). A similar approach has been adopted in earlier research (e.g. de Boer et al., 2008). Preliminary analyses were conducted to ensure no violation of the assumptions of normality (i.e. normal probability plot of the regression standardised residual), linearity and homoscedasticity. Multicollinearity among all study variables was examined and found not to be at a level that would be problematic (unless mentioned) for the planned analyses. All variance inflation factors (VIF) were below 10 and tolerance statistics were above 0.2 (Field, 2005; Brace et al., 2006). An alpha level of $p < 0.05$ was accepted as statistically significant.

Sample Size and Regression Analysis

With regard to sample size requirements and regression analysis there are various schools of thought. According to Brace and colleagues (2006), one argument is to have at least ten participants per predictor variable. However, Tabachnick and Fidell (2007) suggest an alternative approach whereby the number of participants should be determined either by the number of predictors multiplied by 8 plus 50, or the number of predictors plus 104 (whichever is greater). Whilst keeping this in mind, a power calculation was also carried out before the study commenced suggesting a sample of 85 participants (Chapter 3, Methodology, p. 71). As this sample size was not attained ($N = 50$) post-hoc power calculations were computed using internet-based software that used the
effect size (which was calculated), sample size, alpha level, number of predictors and the observed $R^2$ value for each analysis (Soper, 2009). These calculations are reported accordingly.

5.3. Results

5.3.1. Correlation Analyses

*Baseline Correlations*

The relationships among variables was investigated using Pearson product-moment correlation coefficients at baseline (Table 5.1), follow-up time 1 (Table 5.2) and follow-up time 2 (Table 5.3). The correlations at baseline ranged from $r = 0.01$ to $r = 0.63$, indicating no highly significant problems with multicollinearity. Table 5.1 indicates that there were correlations among the main variables and the dependent variables work ability (hypothesis iv) and employment status (hypothesis v). Of the demographic variables, there was a significant negative correlation between age and depression ($r = -0.30$, $p < 0.05$) and age and quality of life ($r = -0.28$, $p < 0.05$). Regarding the psychological and work variables assessed at baseline, there was a significant positive correlation between fatigue and depression ($r = 0.49$, $p < 0.01$) and a significant negative correlation between fatigue and quality of life ($r = -0.28$, $p < 0.05$); depression correlated negatively with quality of life ($r = -0.56$, $p < 0.01$) and cancer self-efficacy ($r = -0.48$, $p < 0.01$); there was a significant positive correlation between cancer self-efficacy and quality of life ($r = 0.63$, $p < 0.01$), and significant positive correlations between work ability and quality of life ($r = 0.60$, $p < 0.01$) and cancer self-efficacy ($r = 0.40$, $p < 0.01$) were found.
Table 5.1: Mean, standard deviations and correlations among the study variables (baseline).

<table>
<thead>
<tr>
<th>Variables</th>
<th>M</th>
<th>SD</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Age</td>
<td>52.49</td>
<td>5.42</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Treatment</td>
<td>0.01</td>
<td></td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Occupation</td>
<td>0.49</td>
<td>0.03</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Fatigue</td>
<td>4.08</td>
<td>1.09</td>
<td>-0.17</td>
<td>0.22</td>
<td>-0.06</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Depression</td>
<td>10.22</td>
<td>5.79</td>
<td>-0.30*</td>
<td>0.20</td>
<td>-0.02</td>
<td>0.49**</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Quality of Life</td>
<td>67.22</td>
<td>11.53</td>
<td>0.28*</td>
<td>0.06</td>
<td>0.27</td>
<td>-0.28*</td>
<td>-0.56**</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Cancer self-efficacy</td>
<td>6.86</td>
<td>1.75</td>
<td>0.27</td>
<td>0.09</td>
<td>0.23</td>
<td>-0.10</td>
<td>-0.48**</td>
<td>0.63**</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Work Ability</td>
<td>5.08</td>
<td>2.18</td>
<td>0.08</td>
<td>-0.01</td>
<td>0.54**</td>
<td>-0.17</td>
<td>-0.22</td>
<td>0.60**</td>
<td>0.40**</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Job self-efficacy</td>
<td>6.44</td>
<td>1.98</td>
<td>0.16</td>
<td>0.16</td>
<td>0.24</td>
<td>-0.19</td>
<td>-0.27</td>
<td>0.62**</td>
<td>0.47**</td>
<td>0.63**</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>10. Employment Status</td>
<td>0.07</td>
<td>-0.03</td>
<td>0.24</td>
<td>0.24</td>
<td>-0.04</td>
<td>0.36*</td>
<td>0.36**</td>
<td>0.45**</td>
<td>0.53**</td>
<td>-</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p < 0.05, **p < 0.01 (2-tailed), N = 50.
Follow-up time 1 Correlations

Correlations among study variables at follow-up time 1 ranged between $r = 0.01$ and $r = 0.82$, suggesting a concern regarding the issue of collinearity. As shown in Table 5.2 there was a significant negative correlation between quality of life and depression ($r = -0.82, p < 0.01$). Consequently, when compared with depression, quality of life correlated most highly with job self-efficacy ($r = 0.63, p < 0.01$), work ability ($r = 0.62$) and employment status ($r = 0.56, p < 0.05$) (to be entered as dependent variables), therefore, depression was omitted from subsequent follow-up time 1 regression analyses. Once again correlations were detected between variables. When considering the correlations between the dependent variables, Table 5.2 indicates that there was a negative correlation between treatment and work ability ($r = -0.29, p < 0.05$). Regarding the psychological and work variables assessed at follow-up time 1, fatigue correlated significantly with cancer self-efficacy ($r = -0.48, p < 0.01$), work ability ($r = -0.53, p < 0.01$), job self-efficacy ($r = -0.54, n = 49, p < 0.01$) and employment status ($r = -0.43, p < 0.01$). Depression was found to be negatively correlated with work ability ($r = -0.45, p < 0.01$), job self-efficacy ($r = -0.59, p < 0.01$) and employment status ($r = -0.44, p < 0.01$). There was a medium correlation between cancer self-efficacy and work ability ($r = 0.35, p < 0.05$) and a strong correlation between cancer self-efficacy and job self-efficacy ($r = 0.50, p < 0.01$); however, this still suggests that the two measures are distinct from one another. Finally, positive correlations were found between work ability and job self-efficacy ($r = 0.68, p < 0.01$), work ability and employment status ($r = 0.69, p < 0.01$) and job self-efficacy and employment status ($r = 0.49, p < 0.01$).
Table 5.2: Mean, standard deviations and correlations among the study variables (follow-up time 1).

<table>
<thead>
<tr>
<th>Variables</th>
<th>$M$</th>
<th>$SD$</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Age</td>
<td>52.49</td>
<td>5.42</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Treatment</td>
<td>0.27</td>
<td></td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Occupation</td>
<td>0.05</td>
<td>-0.02</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Fatigue</td>
<td>4.57</td>
<td>1.32</td>
<td>-0.18</td>
<td>0.34*</td>
<td>-0.11</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Depression</td>
<td>9.51</td>
<td>5.93</td>
<td>-0.21</td>
<td>0.22</td>
<td>-0.01</td>
<td>0.65**</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Quality of Life</td>
<td>70.18</td>
<td>12.75</td>
<td>0.15</td>
<td>-0.22</td>
<td>0.22</td>
<td>-0.66**</td>
<td>-0.82**</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Cancer self-efficacy</td>
<td>7.37</td>
<td>1.29</td>
<td>0.16</td>
<td>-0.19</td>
<td>0.01</td>
<td>-0.48**</td>
<td>-0.50**</td>
<td>0.62**</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Work Ability</td>
<td>4.98</td>
<td>2.44</td>
<td>0.03</td>
<td>-0.29*</td>
<td>0.29*</td>
<td>-0.53**</td>
<td>-0.45**</td>
<td>0.62**</td>
<td>0.35*</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Job self-efficacy</td>
<td>6.49</td>
<td>1.78</td>
<td>0.12</td>
<td>-0.15</td>
<td>0.31*</td>
<td>-0.54**</td>
<td>-0.59**</td>
<td>0.63**</td>
<td>0.50**</td>
<td>0.68**</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>10. Employment Status</td>
<td>0.20</td>
<td>-0.21</td>
<td>0.32*</td>
<td>-0.43**</td>
<td>-0.44**</td>
<td>0.56**</td>
<td>0.26</td>
<td>0.69**</td>
<td>0.49**</td>
<td>-</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p < 0.05, **p < 0.01 (2-tailed), n = 49.
Follow-up Time 2 Correlations

Correlations among the study variables at follow-up time 2 are presented in Table 5.3; these ranged between $r = 0.01$ and $r = 0.80$. Once again, there was a highly significant, negative correlation between depression and quality of life ($r = -0.80, p < 0.01$). Therefore, depression was omitted from subsequent analyses. Positive correlations between occupation and work ability ($r = 0.29, p < 0.05$) and occupation and employment status ($r = 0.40, p < 0.01$) were identified. With regard to the psychological and work variables assessed at follow-up time 2, fatigue correlated with a number of measures including dependent variables to be used in following regression analyses; work ability ($r = -0.45, p < 0.01$) and employment status ($r = -0.53, p < 0.01$). A medium, positive correlation was found between quality of life and work ability ($r = 0.44, p < 0.01$); whereas, quality of life strongly correlated with employment status ($r = 0.62, p < 0.01$). Cancer self-efficacy significantly correlated with work ability ($r = 0.45, p < 0.01$) and employment status ($r = 0.32, p < 0.05$). There were strong, positive correlations between work ability and employment status ($r = 0.66, p < 0.01$) and between work ability and job self-efficacy ($r = 0.62, p < 0.01$). Finally, there was a strong, positive correlation between employment status and job self-efficacy ($r = 0.57, p < 0.01$).
## Table 5.3: Mean, standard deviations and correlations among the study variables (follow-up time 2).

<table>
<thead>
<tr>
<th>Variables</th>
<th>M</th>
<th>SD</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Age</td>
<td>52.49</td>
<td>5.42</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Treatment</td>
<td></td>
<td></td>
<td>-0.02</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Occupation</td>
<td></td>
<td></td>
<td>0.05</td>
<td>-0.02</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Fatigue</td>
<td>3.95</td>
<td>1.37</td>
<td>-0.06</td>
<td>0.36**</td>
<td>-0.07</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Depression</td>
<td>7.73</td>
<td>5.02</td>
<td>-0.25</td>
<td>0.02</td>
<td>0.15</td>
<td>0.60**</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Quality of Life</td>
<td>76.06</td>
<td>11.33</td>
<td>0.17</td>
<td>-0.27</td>
<td>0.04</td>
<td>-0.63**</td>
<td>-0.80**</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Cancer self-efficacy</td>
<td>7.85</td>
<td>1.05</td>
<td>0.03</td>
<td>-0.08</td>
<td>0.01</td>
<td>-0.42**</td>
<td>-0.47**</td>
<td>0.58**</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Work Ability</td>
<td>6.22</td>
<td>2.03</td>
<td>-0.12</td>
<td>-0.25</td>
<td>0.29*</td>
<td>-0.45**</td>
<td>-0.22</td>
<td>0.44**</td>
<td>0.45**</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Job self-efficacy</td>
<td>7.49</td>
<td>1.17</td>
<td>0.04</td>
<td>-0.09</td>
<td>0.23</td>
<td>-0.41**</td>
<td>-0.50**</td>
<td>0.66**</td>
<td>0.64**</td>
<td>0.62**</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>10. Employment Status</td>
<td></td>
<td></td>
<td>0.07</td>
<td>-0.38**</td>
<td>0.40**</td>
<td>0.53**</td>
<td>-0.39**</td>
<td>0.62**</td>
<td>0.32*</td>
<td>0.66**</td>
<td>0.57**</td>
<td>-</td>
</tr>
</tbody>
</table>

*<i>p < 0.05</i>, **<i>p < 0.01</i> (2-tailed), n = 49.
5.4. Factors Predicting Job Self-Efficacy

Hypothesis iii) Cancer self-efficacy and job self-efficacy may be inherently different.

Prior to analysing factors related to work ability, it was important to investigate the factors related to job self-efficacy. This helped to ascertain whether the domains of cancer self-efficacy and job self-efficacy were inherently different. Hierarchical regression was carried out on data at each time point (baseline, follow-up time 1 and follow-up time 2) to assess the ability of cancer self-efficacy, fatigue, depression (baseline only) and quality of life to predict levels of job self-efficacy, after controlling for the influence of age and occupation.

Baseline

Table 5.4 presents results from the baseline hierarchical regression analysis. Age and occupation were entered at Step 1 and explained 20% (Adjusted $R^2 = 0.20$) $F(2, 46) = 7.21, p = 0.002$ of the variance in job self-efficacy. After controlling for age and occupation, the four psychosocial measures (cancer self-efficacy, fatigue, depression and quality of life) explained an additional 25% of the variance in job self-efficacy, $R^2$ change = 0.25, $F$ change (4, 42) = 5.11, $p = 0.002$. In the final model, occupation and quality of life were statistically significant. Examination of the individual betas showed that increased quality of life ($\beta = 0.56, t = 3.52, p = 0.01$) and being employed in a non manual occupation ($\beta = 0.31, t = 2.60, p = 0.001$) was associated with higher perceptions of job self-efficacy at baseline. The observed power for this hierarchical regression analysis was 0.92 with a medium effect size (0.37).
Table 5.4: Hierarchical multiple regression analysis of variables associated with job self-efficacy (dependent variable) at baseline (N = 50).

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>1.90</td>
<td>2.53</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>0.05</td>
<td>0.48</td>
<td>0.16</td>
</tr>
<tr>
<td>Occupation</td>
<td>1.97</td>
<td>0.56</td>
<td>0.45**</td>
</tr>
<tr>
<td>R²</td>
<td>0.23</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ΔR²</td>
<td>0.20</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>-0.78</td>
<td>3.03</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>0.04</td>
<td>0.04</td>
<td>0.12</td>
</tr>
<tr>
<td>Occupation</td>
<td>1.33</td>
<td>0.51</td>
<td>0.31*</td>
</tr>
<tr>
<td>Cancer self-efficacy</td>
<td>-0.04</td>
<td>0.21</td>
<td>-0.03</td>
</tr>
<tr>
<td>Fatigue</td>
<td>-0.07</td>
<td>0.23</td>
<td>-0.04</td>
</tr>
<tr>
<td>Depression</td>
<td>0.01</td>
<td>0.05</td>
<td>0.03</td>
</tr>
<tr>
<td>Quality of life</td>
<td>0.09</td>
<td>0.03</td>
<td>0.56**</td>
</tr>
<tr>
<td>R²</td>
<td>0.49</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ΔR²</td>
<td>0.42</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

ΔR² adjusted R², *p < 0.01, **p < 0.001.

Follow-up Time 1

Results from the hierarchical regression analysis at follow-up time 1 are presented in Table 5.5. Age and occupation were entered at Step 1 and explained 7% (Adjusted R² = 0.07), F (2, 46) = 2.73, p = 0.07 of the variance in job self-efficacy. After controlling for age and occupation, cancer self-efficacy, fatigue, depression and quality of life at follow-up time 1 explained an additional 40% of the variance in job self-efficacy, R² change = 0.40, F change (4, 42) = 8.60, p = 0.0005. In the final model, occupation was the only statistically significant predictor of job self-efficacy at follow-up time 1, where being employed in a non manual job was associated with increased job self-efficacy levels (β = 0.27, t = 2.24, p = 0.03). The observed power for the addition of the independent variables entered at Step 2 to the overall hierarchical model was 0.99 with an effect size of 0.66.
Follow-up Time 2

Results from the hierarchical regression analysis at follow-up time 2 are presented in Table 5.6. Age and occupation were entered at Step 1 and explained just 1% (Adjusted $R^2 = 0.01$), $F (2, 46) = 1.26, p = 0.29$ of the variance in job self-efficacy. Cancer self-efficacy, fatigue and quality of life scores collected at follow-up time 2 explained an additional 54% of the variance in job self-efficacy, after controlling for age and occupation, $R^2$ change = 0.54, $F$ change (3, 43) = 19.24, $p = 0.0005$. In the final model, quality of life, cancer self-efficacy and occupation were statistically significant. Examination of the individual betas showed that increased quality of life ($\beta = 0.48, t = 3.41$, $p = 0.001$) and increased cancer self-efficacy ($\beta = 0.39, t = 3.26, p = 0.002$) and being employed in a non manual occupation ($\beta = 0.21, t = 2.18, p = 0.04$) were associated with higher levels of job self-efficacy. The observed power for the addition of the independent variables entered at Step 2 to the overall hierarchical model was 1.00 with an observed effect size of 1.41.
Table 5.6: Hierarchical multiple regression analysis of variables associated with job self-efficacy (dependent variable) at follow-up time 2 (n = 49).

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>6.76</td>
<td>1.66</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>0.01</td>
<td>0.03</td>
<td>0.27</td>
</tr>
<tr>
<td>Occupation</td>
<td>0.58</td>
<td>0.37</td>
<td>0.22</td>
</tr>
<tr>
<td>R²</td>
<td>0.05</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ΔR²</td>
<td>0.01</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>0.27</td>
<td>1.74</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>-0.01</td>
<td>0.02</td>
<td>-0.06</td>
</tr>
<tr>
<td>Occupation</td>
<td>0.55</td>
<td>0.25</td>
<td>0.21*</td>
</tr>
<tr>
<td>Cancer self-efficacy</td>
<td>0.43</td>
<td>0.13</td>
<td>0.39**</td>
</tr>
<tr>
<td>Fatigue</td>
<td>0.07</td>
<td>0.11</td>
<td>0.07</td>
</tr>
<tr>
<td>Quality of life</td>
<td>0.05</td>
<td>0.01</td>
<td>0.48***</td>
</tr>
<tr>
<td>R²</td>
<td>0.59</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ΔR² adjusted</td>
<td>0.55</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

ΔR² adjusted R², *p < 0.05, **p < 0.01, ***p < 0.001.

In sum, as cancer self-efficacy was only related to job self-efficacy at follow-up time 2, these variables were entered as separate predictors in subsequent work ability and employment status regression models.

5.5. Factors Predicting Work Ability

Hypothesis iv) Levels of self-efficacy and psychosocial well-being will be associated with perceived work ability (cross-sectional and longitudinal).

To test the above mentioned hypothesis, hierarchical regression analyses were carried out on data at each time point (baseline, follow-up time 1 and follow-up time 2) to assess the ability of job self-efficacy, cancer self-efficacy, fatigue, depression (baseline only) and quality of life to predict levels of work ability, after controlling for the influence of age, occupation (0 = manual and 1 = non manual), and treatment group (0 = surgery alone, 1 = chemotherapy; or chemotherapy plus surgery; or radiotherapy plus surgery, or chemotherapy plus surgery and radiotherapy).
Baseline

Results from the hierarchical regression analysis at baseline are presented in Table 5.7. Age, occupation and treatment were entered at Step 1 and explained 26% (Adjusted $R^2 = 0.26$), $F(3, 46) = 6.70$, $p = 0.001$ of the variance in perceived work ability. Measures of job self-efficacy, cancer self-efficacy, fatigue, depression and quality of life scores collected at baseline were entered at Step 2 and explained an additional 27% of the variance in work ability after controlling for age, occupation and treatment, $R^2$ change = 0.27, $F$ change $(5, 41) = 5.17$, $p = 0.001$. In the final model, occupation and quality of life were statistically significant. Examination of the individual betas showed that being employed in a non manual job ($\beta = 0.31$, $t = 2.65$, $p = 0.0005$) and increased quality of life ($\beta = 0.42$, $t = 2.57$, $p = 0.01$) were associated with increased levels of work ability. The observed power for the addition of the independent variables entered at Step 2 to the overall hierarchical model was sufficient (0.94) with an effect size of 0.45.
Table 5.7: Hierarchical multiple regression analysis of variables associated with work ability as the dependent variable at baseline (N= 50).

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>2.08</td>
<td>2.66</td>
<td>0.06</td>
</tr>
<tr>
<td>Age</td>
<td>0.02</td>
<td>0.05</td>
<td>0.06</td>
</tr>
<tr>
<td>Occupation</td>
<td>2.61</td>
<td>0.59</td>
<td>0.55**</td>
</tr>
<tr>
<td>Treatment</td>
<td>-0.12</td>
<td>0.50</td>
<td>-0.03</td>
</tr>
<tr>
<td>R²</td>
<td>0.30</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ΔR²</td>
<td>0.26</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>-1.85</td>
<td>3.01</td>
<td>-0.07</td>
</tr>
<tr>
<td>Age</td>
<td>-0.03</td>
<td>0.04</td>
<td>-0.07</td>
</tr>
<tr>
<td>Occupation</td>
<td>1.49</td>
<td>0.56</td>
<td>0.31**</td>
</tr>
<tr>
<td>Treatment</td>
<td>-0.45</td>
<td>0.45</td>
<td>-0.11</td>
</tr>
<tr>
<td>Cancer self-eficacy</td>
<td>0.01</td>
<td>0.17</td>
<td>0.01</td>
</tr>
<tr>
<td>Job self-efficacy</td>
<td>0.29</td>
<td>0.16</td>
<td>0.27</td>
</tr>
<tr>
<td>Fatigue</td>
<td>-0.04</td>
<td>0.25</td>
<td>-0.02</td>
</tr>
<tr>
<td>Depression</td>
<td>0.04</td>
<td>0.05</td>
<td>0.10</td>
</tr>
<tr>
<td>Quality of life</td>
<td>0.08</td>
<td>0.03</td>
<td>0.42*</td>
</tr>
<tr>
<td>R²</td>
<td>0.57</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ΔR²</td>
<td>0.49</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

ΔR² adjusted R², *p < 0.01, **p < 0.0005.

Follow-up Time 1

Results from the hierarchical regression analysis at follow-up time 1 are presented in Table 5.8. A substantial bivariate correlation was found between measures of depression and quality of life (r = -0.82); therefore, this raised the issue of collinearity. As a result, depression was omitted. Age, occupation and treatment were entered at Step 1 and explained 14% (Adjusted R² = 0.14), F (3, 45) = 3.50, p = 0.02 of the variance in perceived work ability. Measures of job self-efficacy, cancer self-efficacy, fatigue and quality of life scores collected at follow-up time 1 were entered at Step 2 and explained an additional 45% of the variance in work ability after controlling for age, occupation and treatment, R² change = 0.45, F change (4, 41) = 13.14, p = 0.0005. In the final model, job self-efficacy and treatment type were statistically significant. Examination of the...
individual betas showed that greater levels of job self-efficacy ($\beta = 0.57$, $t = 4.40$, $p = 0.0005$) was associated with better perceived work ability.

Regarding treatment, those receiving anything other than surgery alone had poorer work ability when compared with those who only received surgical treatment ($\beta = -0.19$, $t = -1.94$, $p = 0.05$). The observed power for the addition of the independent variables entered at Step 2 to the overall hierarchical model was 0.99 with an effect size of 1.07.

Table 5.8: Hierarchical multiple regression analysis of variables associated with work ability as the dependent variable at follow-up time 1 ($n = 49$).

<table>
<thead>
<tr>
<th>Variable</th>
<th>$B$</th>
<th>SE $B$</th>
<th>$\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>4.39</td>
<td>3.27</td>
<td>0.02</td>
</tr>
<tr>
<td>Age</td>
<td>0.01</td>
<td>0.06</td>
<td>0.02</td>
</tr>
<tr>
<td>Occupation</td>
<td>1.63</td>
<td>0.72</td>
<td>0.23*</td>
</tr>
<tr>
<td>Treatment</td>
<td>-1.49</td>
<td>0.62</td>
<td>-0.32*</td>
</tr>
<tr>
<td>R²</td>
<td>0.19</td>
<td></td>
<td></td>
</tr>
<tr>
<td>$\Delta R^2$</td>
<td>0.14</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>1.19</td>
<td>3.52</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>-0.03</td>
<td>0.04</td>
<td>-0.07</td>
</tr>
<tr>
<td>Occupation</td>
<td>0.33</td>
<td>0.54</td>
<td>0.06</td>
</tr>
<tr>
<td>Treatment</td>
<td>-0.91</td>
<td>0.47</td>
<td>-0.19*</td>
</tr>
<tr>
<td>Cancer self-efficacy</td>
<td>-0.34</td>
<td>0.24</td>
<td>-0.18</td>
</tr>
<tr>
<td>Job self-efficacy</td>
<td>0.78</td>
<td>0.18</td>
<td>0.57**</td>
</tr>
<tr>
<td>Fatigue</td>
<td>-0.13</td>
<td>0.25</td>
<td>-0.07</td>
</tr>
<tr>
<td>Quality of life</td>
<td>0.05</td>
<td>0.03</td>
<td>0.28</td>
</tr>
<tr>
<td>R²</td>
<td>0.64</td>
<td></td>
<td></td>
</tr>
<tr>
<td>$\Delta R^2$</td>
<td>0.58</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

$\Delta R^2$ adjusted $R^2$, *$p < 0.05$, **$p < 0.0005$.

**Follow-up Time 2**

Results from the hierarchical regression analysis at follow-up time 2 are presented in Table 5.9. A substantial bivariate correlation was found between measures of depression and quality of life ($r = -0.80$); therefore, this raised the issue of collinearity. As a result, depression was omitted. Age, occupation and
treatment were entered at Step 1 and explained 11% (Adjusted $R^2 = 0.11$), $F(3, 45) = 3.45, p = 0.04$ of the variance in perceived work ability. Measures of job self-efficacy, cancer self-efficacy, fatigue and quality of life scores collected at follow-up time 2 were entered at Step 2 and explained an additional 34% of the variance in work ability after controlling for age, occupation and treatment, $R^2$ change $= 0.34$, $F$ change $(4, 41) = 7.22, p = 0.0005$. In the final model, job self-efficacy was the only predictor that reached statistical significance.

Examination of the individual betas showed that increased levels of job self-efficacy ($\beta = 0.50, t = 2.92, p = 0.006$) was associated with better perceived work ability. The observed power for the addition of the independent variables entered at Step 2 to the overall hierarchical model was 0.98 with an effect size of 0.56.

<table>
<thead>
<tr>
<th>Variable</th>
<th>$B$</th>
<th>SE $B$</th>
<th>$\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>8.57</td>
<td>2.76</td>
<td>-0.13</td>
</tr>
<tr>
<td>Age</td>
<td>-0.05</td>
<td>0.05</td>
<td>-0.14</td>
</tr>
<tr>
<td>Occupation</td>
<td>1.32</td>
<td>0.61</td>
<td>0.29</td>
</tr>
<tr>
<td>Treatment</td>
<td>-1.06</td>
<td>0.59</td>
<td>-0.24</td>
</tr>
<tr>
<td>$R^2$</td>
<td>0.16</td>
<td></td>
<td></td>
</tr>
<tr>
<td>$\Delta R^2$</td>
<td>0.11</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>3.75</td>
<td>3.41</td>
<td>-0.14</td>
</tr>
<tr>
<td>Age</td>
<td>-0.05</td>
<td>0.04</td>
<td>-0.14</td>
</tr>
<tr>
<td>Occupation</td>
<td>0.77</td>
<td>0.52</td>
<td>0.17</td>
</tr>
<tr>
<td>Cancer self-efficacy</td>
<td>0.15</td>
<td>0.29</td>
<td>0.08</td>
</tr>
<tr>
<td>Job self-efficacy</td>
<td><strong>0.88</strong></td>
<td><strong>0.30</strong></td>
<td><strong>0.50</strong></td>
</tr>
<tr>
<td>Fatigue</td>
<td>-0.32</td>
<td>0.22</td>
<td>-0.21</td>
</tr>
<tr>
<td>Quality of life</td>
<td>-0.02</td>
<td>0.03</td>
<td>-0.09</td>
</tr>
<tr>
<td>$R^2$</td>
<td>0.51</td>
<td></td>
<td></td>
</tr>
<tr>
<td>$\Delta R^2$</td>
<td>0.43</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

$\Delta R^2$ adjusted $R^2$, *$p < 0.01$. 

Table 5.9: Hierarchical multiple regression analysis of variables associated with work ability as the dependent variable at follow-up time 2 ($n = 49$).
Prospective Analysis: Predictors of Work Ability

A prospective hierarchical regression analysis was conducted to examine whether baseline psychosocial and work measures predicted work ability scores at follow-up time 2 (whilst controlling for age, occupation and treatment). Table 5.10 shows the longitudinal hierarchical regression assessing baseline predictors of work ability at follow-up time 2. Baseline age, occupation and treatment were entered at Step 1 and explained 11% (Adjusted $R^2 = 0.11$), $F (3, 45) = 2.96, p = 0.04$ of the variation work ability scores at follow-up time 2.

Table 5.10: Longitudinal Hierarchical Regression analysis for work ability at follow-up time 2 ($n = 49$).

<table>
<thead>
<tr>
<th>Variable</th>
<th>$B$</th>
<th>SE $B$</th>
<th>$\beta$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>8.57</td>
<td>2.76</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>-0.05</td>
<td>0.05</td>
<td>-0.13</td>
</tr>
<tr>
<td>Occupation</td>
<td>1.32</td>
<td>0.61</td>
<td>0.30*</td>
</tr>
<tr>
<td>Treatment</td>
<td>-1.06</td>
<td>0.59</td>
<td>-0.24</td>
</tr>
<tr>
<td>$R^2$</td>
<td>0.16</td>
<td></td>
<td></td>
</tr>
<tr>
<td>$\Delta R^2$</td>
<td>0.11</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>6.59</td>
<td>3.04</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>-0.07</td>
<td>0.04</td>
<td>-0.18</td>
</tr>
<tr>
<td>Occupation</td>
<td>-0.31</td>
<td>0.61</td>
<td>-0.07</td>
</tr>
<tr>
<td>Treatment</td>
<td>-1.03</td>
<td>0.52</td>
<td>-0.24*</td>
</tr>
<tr>
<td>Fatigue†</td>
<td>-0.22</td>
<td>0.25</td>
<td>-0.12</td>
</tr>
<tr>
<td>Quality of life†</td>
<td>0.03</td>
<td>0.03</td>
<td>0.15</td>
</tr>
<tr>
<td>Depression†</td>
<td>0.05</td>
<td>0.06</td>
<td>0.15</td>
</tr>
<tr>
<td>Cancer self-efficacy†</td>
<td>0.01</td>
<td>0.18</td>
<td>0.01</td>
</tr>
<tr>
<td>Job self-efficacy†</td>
<td>-0.09</td>
<td>0.16</td>
<td>-0.09</td>
</tr>
<tr>
<td>Work Ability†</td>
<td>0.62</td>
<td>0.16</td>
<td>0.67**</td>
</tr>
<tr>
<td>$R^2$</td>
<td>0.52</td>
<td></td>
<td></td>
</tr>
<tr>
<td>$\Delta R^2$</td>
<td>0.42</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

† Baseline score, $\Delta R^2$ adjusted $R^2$, *$p < 0.05$, **$p < 0.0005$.

Baseline assessments of work ability, fatigue, quality of life, depression, cancer self-efficacy and job self-efficacy and depression scores were entered at Step 2 and explained an additional 36% of the variance in follow-up time 2 work ability scores.
scores, $R^2$ change = 0.36, $F$ change (6, 39) = 4.98, $p = 0.001$. High work ability at baseline was associated with ($\beta = 0.67$, $t = 3.99$, $p = 0.0005$) greater work ability at follow-up time 2. Similarly, treatment type; whereby being treated with chemotherapy; or chemotherapy plus surgery; or radiotherapy plus surgery, or chemotherapy plus surgery and radiotherapy ($\beta = -0.24$, $t = -1.99$, $p = 0.05$) predicted poorer work ability outcomes at follow-up time 2. The observed power for the addition of the independent variables entered at Step 2 to the overall hierarchical model was sufficient (0.93) with an effect size of 0.53.

5.6. Factors Predicting Employment Status

**Hypothesis v) Levels of self-efficacy, psychosocial well-being and work ability will be associated with employment status (cross-sectional and longitudinal).**

To examine the above mentioned hypothesis, hierarchical logistic regression models were used to identify explanatory variables significantly associated with the dependent variable ‘employment status’ (0 = not working 1 = working) for each time point (baseline, follow-up time 1 and follow-up time 2). To minimise the number of independent variables in the final model, two steps were undertaken. Firstly, an analysis was conducted to identify the psychosocial variables that were significantly related to employment status at each time point. Based upon these results, variables that emerged as significant factors were then added to the final model that contained the work variables (work ability and job self-efficacy). All models adjusted for age, occupation and treatment (Block 1).

**Baseline**

At baseline a total of 12 participants described their employment status as working. Table 5.11 shows the results from the final hierarchical logistic regression analysis at baseline. A total of 50 cases were analysed. Age, occupation and treatment group were entered in Block 1 and explained between 9% and 15% of the variance in employment status. However, this model was not found to be statistically different when compared against a constant-only model ($\chi^2 = 5.22$, df = 3, $p = 0.16$). The model considering psychosocial variables was found to be significant ($\chi^2 = 14.07$, df = 7, $p = 0.05$); however,
none of the psychosocial variables (fatigue, depression, quality of life or cancer self-efficacy) were statistically related to employment status at baseline. Therefore, none of these were included in the final model. Explanatory variables included in Block 2 of the final model included baseline scores of job self-efficacy and work ability. The final model presented in Table 5.11 led to a significant outcome \( \chi^2 = 21.80, \text{df} = 5, \ p = 0.001 \). The model accounted for between 35% and 53% of the variance in employment status, with 92% of the not working participants accurately predicted. Overall the model accurately classified 84% of the cases. Only job self-efficacy reliably predicted employment status (OR = 2.20, 95% CI: 1.17 – 4.13); this indicated that at baseline, participants who had lower job self-efficacy were over 2 times more likely not to be working than those who had higher levels of job self-efficacy.

**Table 5.11: Hierarchical Logistic Regression variables related to employment status at baseline \( (N = 50) \).**

<table>
<thead>
<tr>
<th>Variable</th>
<th>( B )</th>
<th>SE ( B )</th>
<th>OR</th>
<th>95% C.I. for OR</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Lower</td>
</tr>
<tr>
<td><strong>Block 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>-0.07</td>
<td>3.56</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>-0.01</td>
<td>0.07</td>
<td>0.99</td>
<td>0.87</td>
</tr>
<tr>
<td>Occupation</td>
<td>-1.81</td>
<td>1.11</td>
<td>0.35</td>
<td>0.06</td>
</tr>
<tr>
<td>Treatment</td>
<td>-1.04</td>
<td>0.87</td>
<td>0.16</td>
<td>0.02</td>
</tr>
<tr>
<td>Cox &amp; Snell R(^2)</td>
<td>0.09</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nagelkerke R(^2)</td>
<td>0.15</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Block 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>-3.42</td>
<td>4.46</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>-0.11</td>
<td>0.09</td>
<td>0.89</td>
<td>0.75</td>
</tr>
<tr>
<td>Occupation</td>
<td>-0.42</td>
<td>1.61</td>
<td>0.66</td>
<td>0.03</td>
</tr>
<tr>
<td>Treatment</td>
<td>-1.26</td>
<td>1.11</td>
<td>0.28</td>
<td>0.03</td>
</tr>
<tr>
<td>JSE</td>
<td>\textbf{0.79}</td>
<td>\textbf{0.32}</td>
<td>\textbf{2.20*}</td>
<td>\textbf{1.17}</td>
</tr>
<tr>
<td>WA</td>
<td>0.45</td>
<td>0.29</td>
<td>1.56</td>
<td>0.88</td>
</tr>
<tr>
<td>Cox &amp; Snell R(^2)</td>
<td>0.35</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nagelkerke R(^2)</td>
<td>0.53</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

JSE Job self-efficacy, WA Work ability, OR odds ratio, CI confidence interval, *\( p < 0.001 \).
Follow-up Time 1

At follow-up time 1 there were only 9 participants who described their employment status as working; therefore, this number was deemed to be insufficient to carry out analysis for this time point.

Follow-up time 2

Table 5.12 shows the results from the hierarchical logistic regression analysis assessing variables related to employment status at follow-up time 2. A total of 49 cases were analysed. Nineteen participants were working at this time point. Age, occupation and treatment group were entered in Block 1 (variables controlled for) and explained between 32% and 44% of the variance in employment status at follow-up time 2. This model was found to be statistically different when compared against a constant-only model ($X^2 = 19.17, \ df = 3, \ p = 0.0005$). When assessing psychosocial variables (fatigue, quality of life and cancer self-efficacy) a significant model emerged ($X^2 = 25.88, \ df = 6, \ p = 0.0005$) where only quality of life was significant; therefore, quality of life was included in the final model. The final model which is shown in Table 5.12 was found to be significant ($X^2 = 45.60, \ df = 6, \ p = 0.0005$). The model accounted for between 61% and 82% of the variance in employment status, with 93% of the not working participants accurately predicted. Overall, the model accurately classified 92% of the cases. Work ability (OR = 3.05, 95% CI: 1.00 – 12.80) and occupation (OR = 0.03, 95% CI: 0.00 – 0.86) were statistically associated with employment status.
Table 5.12: Hierarchical Logistic Regression variables related to employment status at follow-up time 2 (n = 49).

<table>
<thead>
<tr>
<th>Variable</th>
<th>$B$</th>
<th>SE</th>
<th>OR</th>
<th>95% C.I. for OR</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Lower</td>
</tr>
<tr>
<td><strong>Block 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>-4.52</td>
<td>3.96</td>
<td></td>
<td>0.94</td>
</tr>
<tr>
<td>Age</td>
<td>0.08</td>
<td>0.07</td>
<td>1.08</td>
<td>0.94</td>
</tr>
<tr>
<td>Occupation</td>
<td>-3.33</td>
<td>1.26</td>
<td>0.03**</td>
<td>0.00</td>
</tr>
<tr>
<td>Treatment</td>
<td>2.21</td>
<td>0.89</td>
<td>9.09**</td>
<td>1.59</td>
</tr>
<tr>
<td>QOL</td>
<td>0.32</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>JSE</td>
<td>-1.05</td>
<td>1.08</td>
<td>0.35</td>
<td>0.04</td>
</tr>
<tr>
<td>WA</td>
<td>1.28</td>
<td>0.65</td>
<td>3.05*</td>
<td>1.00</td>
</tr>
<tr>
<td><strong>Block 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>-25.55</td>
<td>10.82</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>0.07</td>
<td>0.13</td>
<td>1.08</td>
<td>0.83</td>
</tr>
<tr>
<td>Occupation</td>
<td>-3.37</td>
<td>1.64</td>
<td>0.03*</td>
<td>0.00</td>
</tr>
<tr>
<td>Treatment</td>
<td>1.10</td>
<td>1.41</td>
<td>3.00</td>
<td>0.19</td>
</tr>
<tr>
<td>QOL</td>
<td>0.28</td>
<td>0.15</td>
<td>1.32</td>
<td>0.99</td>
</tr>
<tr>
<td>JSE</td>
<td>-1.05</td>
<td>1.08</td>
<td>0.35</td>
<td>0.04</td>
</tr>
<tr>
<td>WA</td>
<td>1.28</td>
<td>0.65</td>
<td>3.05*</td>
<td>1.00</td>
</tr>
<tr>
<td>Cox &amp; Snell R²</td>
<td>0.61</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nagelkerke R²</td>
<td>0.44</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

QOL Quality of life, JSE Job self-efficacy, WA Work ability, OR odds ratio, CI confidence interval, *$p < 0.05$, **$p < 0.01$.

**Prospective Analysis: Predictors of Employment Status**

A longitudinal hierarchical logistic regression analysis was conducted to investigate baseline predictors of employment status at follow-up time two. Similar to the cross sectional approach, an analysis was conducted to identify the psychosocial variables that were significantly related to employment status at each time point. Based upon these results, variables that emerged as significant factors were then added to the final model that included contained the work variables (work ability and job self-efficacy).
Hierarchical logistic regression results for prospective predictors of employment status are reported in Table 5.13. A total of 49 cases were analysed. Baseline age, occupation and treatment group were entered in Block 1 (variables controlled for) and explained between 32% and 44% of the variance in employment status at follow-up time 2. This model was found to be statistically different when compared against a constant-only model ($X^2 = 19.17$, df = 3, $p = 0.0005$). Analysis that considered whether any of the baseline psychosocial variables predicted follow-up employment status led to a significant model ($X^2 = 25.88$, df = 6, $p = 0.001$); however, apart from occupation none of the psychosocial variables emerged as statistically significant predictors: therefore, these were not included in the final model. As shown in Table 5.13, the final model that comprised of baseline employment status, work ability and job self-efficacy and controlled for age occupation and treatment led to a significant outcome ($X^2 = 23.36$, df = 6, $p = 0.001$). The model accounted for between 38% and 51% of the variance in employment status, with 86% of the not working participants accurately predicted. The final model accurately classified 80% of cases. Receiving chemotherapy; or chemotherapy plus surgery; or radiotherapy plus surgery, or chemotherapy plus surgery and radiotherapy (OR = 9.91, 95% CI: 1.57 – 62.50) was associated with a greater likelihood of not working at follow-up time 2.
Table 5.13: Longitudinal Hierarchical Logistic Regression variables related to follow-up time 2 employment status ($n = 49$).

<table>
<thead>
<tr>
<th>Variable</th>
<th>$B$</th>
<th>SE $B$</th>
<th>OR</th>
<th>95% C.I. for OR</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Lower</td>
<td>Upper</td>
</tr>
<tr>
<td><strong>Block 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>-4.52</td>
<td>3.96</td>
<td>0.94</td>
<td>1.25</td>
</tr>
<tr>
<td>Age</td>
<td>0.08</td>
<td>0.07</td>
<td>1.08</td>
<td></td>
</tr>
<tr>
<td>Occupation</td>
<td>-3.33</td>
<td>1.26</td>
<td>0.03*</td>
<td>0.00</td>
</tr>
<tr>
<td>Treatment</td>
<td>2.21</td>
<td>0.89</td>
<td>9.09*</td>
<td>1.59</td>
</tr>
<tr>
<td>Cox &amp; Snell R²</td>
<td>0.32</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nagelkerke R²</td>
<td>0.44</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Block 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>-5.59</td>
<td>4.10</td>
<td>0.91</td>
<td>1.23</td>
</tr>
<tr>
<td>Age</td>
<td>0.06</td>
<td>0.08</td>
<td>1.06</td>
<td></td>
</tr>
<tr>
<td>Occupation</td>
<td>-2.27</td>
<td>1.37</td>
<td>0.10</td>
<td>0.01</td>
</tr>
<tr>
<td>Treatment</td>
<td>2.29</td>
<td>0.94</td>
<td>9.91*</td>
<td>1.57</td>
</tr>
<tr>
<td>ES†</td>
<td>-0.27</td>
<td>1.12</td>
<td>0.76</td>
<td>0.08</td>
</tr>
<tr>
<td>JSE†</td>
<td>-0.06</td>
<td>0.29</td>
<td>0.94</td>
<td>0.53</td>
</tr>
<tr>
<td>WA†</td>
<td>0.47</td>
<td>0.26</td>
<td>1.60</td>
<td>0.95</td>
</tr>
<tr>
<td>Cox &amp; Snell R²</td>
<td>0.38</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nagelkerke R²</td>
<td>0.51</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

† Baseline, ES Employment status, JSE Job self-efficacy, WA Work ability, OR odds ratio, CI confidence interval, * $p < 0.01$.

5.7. Discussion

The aim of the study was to examine cross sectional and prospective predictors of work ability and employment status in individuals diagnosed with colorectal cancer. The study adds knowledge to existing cancer and work literature by identifying previously unexplored variables as being associated with employment outcomes. Furthermore, the findings from the study indicate that predictors and variables related to work ability and employment status are likely to alter over time. Moreover, to the researcher’s knowledge, this was the first study to consider the role of self-efficacy, namely, job self-efficacy upon these outcomes in a systematic manner. Variables related to work ability outcomes
cross-sectionally included occupation and quality of life (baseline), treatment type and job self-efficacy (follow-up time 1) and job self-efficacy (follow-up time 2). Meanwhile, variables related to employment status comprised job self-efficacy (baseline) and occupation and work ability (follow-up time 2). Along with self-assessed work ability at baseline, receiving chemotherapy, or a combination of treatments (i.e. not surgery alone) were the strongest predictors of follow-up work ability independent of age and occupation. Finally, treatment type was also identified as the strongest predictor of employment status approximately six months after diagnosis.

The finding that job self-efficacy was related to work ability and employment status indicates that it is a variable that is worthy of consideration in future research endeavours. Prior researchers have only assessed self-efficacy in relation to cancer self-management and adjustment studies (Cunningham et al., 1991). Researchers investigating return to work and work ability have failed to consider the variable altogether (to the researcher’s knowledge), be it cancer-related or work-related self-efficacy. As demonstrated by this study, and supported by Bandura (1997), self-efficacy is likely to be domain-specific; thus perhaps the reason why job self-efficacy alone was related to work ability and employment status. Initial analyses of variables related to job self-efficacy did identify that cancer self-efficacy was related to job self-efficacy at follow-up time 2. This may due to the way participants had had time to adjust to their cancer and treatment (indicated by quality of life) which led to higher perceptions of cancer self-efficacy that resulted in better job self-efficacy beliefs. More favourable perceptions of job self-efficacy were related to higher self-assessed work ability outcomes at follow-up time 1 and time 2. At baseline however quality of life and being employed in a non manual occupation were related to better work ability outcomes. In a sample of breast, testicular and prostate cancer patients Gudbergsson et al. (2008) also reported that quality of life was associated with work ability. Within the context of the current study, this could be explained by the fact that the majority of participants had received surgery when baseline questionnaires were completed (but prior to chemotherapy or radiotherapy); and therefore, it could be argued that quality of life rather than job self-efficacy was more likely to be related to work ability as most patients were
Chap

ter 5

Predictors of Work Ability & Employment Status

recovering following surgery. In other words, when assessing their work ability, patients may have been judging functional capabilities as a result of surgery over and above perceptions of job self-efficacy. In spite of such findings, job self-efficacy was not a significant predictor of work ability in the prospective model. Instead, treatment and work ability at baseline emerged as significant predictors of work ability at follow-up time 2. On the face of it, this is in line with previous research, yet, inherent differences in measures used to assess work ability render it difficult to compare these findings with existing research (Munir, Yarker, et al., 2009).

In contrast to previous research findings, fatigue was not related to job self-efficacy, work ability or employment outcomes (e.g. Pryce et al., 2007; Kessler et al., 2001; Lee et al., 2008; Steiner et al., 2008). An explanation for this may be due to the shorter study duration (six months). However, previous studies that have adopted a cross-sectional design are compromised due to inherent limitations to infer causality and inability to address confounding factors at baseline: to draw such conclusions is therefore difficult. Following this sample beyond treatment would enable fatigue to be investigated as a predictor of work outcomes in the long term. Such findings have been reported in quantitative studies (e.g. Spelten et al., 2003; Steiner et al., 2008; Lee et al., 2008) and suggested by qualitative studies that have interviewed patients a number of years following diagnosis (Maunsell et al., 1999; Main et al., 2005; Kennedy et al., 2007; Amir et al., 2008). Furthermore, this is a matter that may be addressed by the diary study presented in the following chapter.

The findings do however suggest that treatment modality may be a more adequate predictor of work ability and employment status in the six months following diagnosis. In a sample of colorectal cancer patients, Sanchez et al. (2004) also showed that chemotherapy treatment delayed return to work by two months. The prospective nature of this study adds to this cross sectional finding and demonstrates that treatment predicted work ability and employment status longitudinally. Such finding are consistent with de Boer et al. (2008) who also found those receiving chemotherapy or chemotherapy plus radiotherapy and / or surgery exhibited poorer work ability outcomes. Similarly, the results
from the prospective model of employment outcomes also showed that treatment predicted whether an individual was working at follow-up time 2. These findings are in line with prospective return to work studies comprising of breast cancer patients (Balak et al., 2008) and head and neck cancer patients (Buckwalter et al., 2007); however, until now little was known about colorectal cancer patients. Nevertheless, when assessing work ability, these results support the argument posed by prior researchers; that treatment type or receiving multiple treatment modalities may be more important than cancer type (Bradley et al., 2007; Taskila et al., 2007; de Boer et al., 2008).

Summary

In sum, the findings from this study highlight the added value of measuring self-efficacy beliefs in future research considering the impact of cancer on work ability and employment outcomes. Although job self-efficacy did not significantly predict longitudinal work ability and employment outcomes, the finding that it was important cross-sectionally suggests it warrants further investigation. Moreover, following patients beyond the current study time frame (i.e. after completion of treatment) may provide further insight into how this variable may impact upon these work outcomes.
6. **Exploring Temporal Patterns in Cancer Management, Return to Work Intentions and Work Ability: A Diary Study**

6.1. **Introduction**

The overall objective of this thesis was to consider the work ability, return to work intentions and employment outcomes of colorectal cancer patients in the UK. Chapter 4 provided results from the quantitative questionnaires which sought to monitor changes in patients’ self-efficacy, psychosocial well-being and employment outcomes over the six month study period. Furthermore, the results suggested that there were variations in psychosocial and work outcomes; as a result, it could be argued that this may result in varying return to work intentions over time. Similarly, findings presented in Chapter 5 suggest that self-efficacy plays a key role, particularly when attempting to understand colorectal patients’ perceived work ability and actual employment status. Moreover, the finding that self-efficacy was only related to work ability and employment status at particular time points further indicates that levels of self-efficacy and the role of such beliefs are likely to alter temporally. Skaalvich and Bong (2003) support this notion further; these researchers argue that experimental findings indicate that self-efficacy perceptions respond to changes in the experience. In evaluation, however, it has been suggested that more systematic research is needed to assess the stability of self-efficacy (Skaalvich & Bong, 2003). Nonetheless, according to Bandura (1997), self-efficacy beliefs are context-specific and for this reason they should not be viewed as a stable personality construct. This has been demonstrated in a group of students; Pajares and Graham (1999) found that students’ self-efficacy levels in relation to their math ability changed significantly over a six month period. Such findings infer that perceptions of self-efficacy are likely to change over time, particularly when changes occur in a given experience (e.g. during a cancer pathway). Subsequently, this was a matter that warranted further investigation in these colorectal cancer patients. It is unlikely that a colorectal cancer
patients experience will not be without its challenges. Furthermore, it can be argued that self-efficacy beliefs will be challenged at certain time points. For example, at diagnosis an individual may feel overwhelmed by what he / she is faced with; yet, once the individual has adjusted to the diagnosis, self-efficacy levels may improve. However, following this, changes in self-efficacy may ensue due the treatment(s) and subsequent side-effects an individual may be required to manage. As a result, it can be suggested that return to work intentions and perceptions of work ability may also alter as a result of temporal changes in self-efficacy beliefs.

It was therefore necessary to understand the more complex psychological phenomena underpinning patients’ experiences and thoughts about managing cancer, its associated treatment and employment intentions. Consequently, in addition to the questionnaire study, a smaller sub-sample of participants completed a monthly diary that coincided with the six month quantitative data collection period. The diaries aimed to capture the more subtle and temporal fluctuations in perceptions of self-efficacy and the factors (e.g. self-management of treatment and symptoms and support) that impacted upon these self-beliefs. In other words, the diaries sought to explore what (if anything) participants may have been doing to self-manage their cancer and work, and more importantly, to understand how their self-efficacy beliefs may shape these behaviours and return to work intentions / outcomes. Adopting this design allowed for a more comprehensive understanding of the area, which is likely to better inform future intervention design in employment and healthcare that would help employees / patients affected by cancer to better manage their work and illness.

The main objective of the diary study was to understand the temporal fluctuations and patterns in cancer self-management, return to work intentions and work ability. In particular, the aims were:

1. To understand the temporal nature of self-efficacy beliefs and how such beliefs may impact upon self-management and subsequent return to work intentions and perceptions of work ability.
2. To consider the level and nature of social support received and whether this may benefit individuals’ self-efficacy beliefs and subsequent self-management and work outcomes.

6.2. Methods

A diary booklet was designed to capture temporal variations in perceptions of self-efficacy in relation to the management of cancer and work, including return to work intentions. According to Pope and Mays (1995), advances in medicine and healthcare have given rise to research questions requiring new methods of study. Consequently, diary methods are a useful tool that can be used over time to capture in-depth data on psychological processes relating to ongoing experiences (Bolger, Davis & Rafaeli, 2003). Both quantitative and qualitative diary methods have been used in a wide variety of settings, including healthcare (Ong & Jinks, 2006) and organisational settings (Harris, Daniels & Briner, 2003). For example, Ong and Jinks (2006) used a qualitative diary (one week) to describe older people’s everyday experiences of living with knee pain and disability. In a similar manner to the current study, these researchers used diaries as part of a mixed-methods design which helped clinicians’ holistic understanding of how this phenomenon may impact patients’ quality of life. In this study, this method provided the opportunity to collect meaningful data in a non-intrusive manner. Additionally, it served to supplement the data captured by the questionnaires by providing a rich insight into the nature of the cancer experience and its impact upon work ability and return to work intentions and employment outcomes.

6.2.1. Participants

A purposive sampling technique was utilised to recruit ten participants. These participants were those who had completed the survey. At the time of recruitment for the survey, all participants were asked if they would like to complete a diary booklet. Ten participants agreed to take part in the diary study. Thus, the inclusion criteria were the same as mentioned earlier in Chapter 3 (pp. 70-71). As this study was qualitative and therefore concerned with understanding individual patient experiences rather than obtaining statistical representation this sample size was adequate (Mays & Pope, 1995).
The diary study’s aims and objectives were outlined in the participant information sheet (Appendix 4). The information sheet explained that participation in the diary study was optional. The informed consent form asked individuals to indicate whether they wished to complete the diary study.

**Participant Characteristics**

Table 6.1 summarises the demographic profiles of the colorectal cancer patients that completed the diary study. The mean age of the participants was 50.50 years (SD = 5.10, range 44 – 58 years) and seven were women (70%).

At baseline, two (20%) had undergone surgical treatment alone, seven (70%) had received surgery and were expecting to receive chemotherapy or radiotherapy and one participant was expecting to receive chemotherapy alone. All ten participants were in employment at diagnosis (full-time = 8), of which six were on sick leave at baseline. In total, 43 out of a possible 60 (72%) diaries were completed (Table 6.1). More than half of all participants (n = 6) completed all six diary booklets. Of the remaining four participants, one completed three; another completed two and the remaining two completed baseline diary booklets alone. The 44-year-old bank clerk who completed two diaries withdrew from the diary study as she felt that the cancer had been dealt with after being given the ‘all clear’ after surgery; the 47-year-old senior manager and 51-year-old car rental assistant failed to complete or return subsequent diary booklets posted after baseline.

**6.2.2. Materials**

The diary booklet was paper-based and was completed by participants on a monthly basis over six months (Appendix 8). Three colorectal consultants and two colorectal nurse specialists provided advice and guidance about the content and design of the diary booklet. Prior to submitting the final set of documents to the research ethics committee, the diary booklet was piloted by two individuals (data not reported here) previously diagnosed with colorectal cancer to assess its content and feasibility. As many participants would be undergoing treatment, it was important to design the diary so it did not take up an excessive amount of their time to complete.
Table 6.1: Demographic profiles of participants (n = 10).

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Gender</th>
<th>Treatment</th>
<th>Employment</th>
<th>Work Status</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(Baseline)</td>
<td>(T1)</td>
</tr>
<tr>
<td>1</td>
<td>56</td>
<td>Male</td>
<td>S &amp; C</td>
<td>Teacher</td>
<td>W</td>
</tr>
<tr>
<td>2</td>
<td>48</td>
<td>Female</td>
<td>S &amp; C</td>
<td>Charity Fundraiser</td>
<td>SL</td>
</tr>
<tr>
<td>3</td>
<td>58</td>
<td>Female</td>
<td>S &amp; C</td>
<td>Teacher</td>
<td>SL</td>
</tr>
<tr>
<td>4</td>
<td>45</td>
<td>Male</td>
<td>S &amp; C</td>
<td>Teacher</td>
<td>SL</td>
</tr>
<tr>
<td>5</td>
<td>44</td>
<td>Female</td>
<td>S</td>
<td>Bank Clerk</td>
<td>W</td>
</tr>
<tr>
<td>6</td>
<td>51</td>
<td>Female</td>
<td>S</td>
<td>Car Rental Assistant</td>
<td>SL</td>
</tr>
<tr>
<td>7</td>
<td>52</td>
<td>Female</td>
<td>S &amp; C</td>
<td>Retail Assistant</td>
<td>SL</td>
</tr>
<tr>
<td>8</td>
<td>47</td>
<td>Male</td>
<td>S, C &amp; R</td>
<td>Senior Manager</td>
<td>SL</td>
</tr>
<tr>
<td>9</td>
<td>57</td>
<td>Female</td>
<td>C</td>
<td>Nurse</td>
<td>W</td>
</tr>
<tr>
<td>10</td>
<td>47</td>
<td>Female</td>
<td>S &amp; C</td>
<td>Policy Advisor</td>
<td>W</td>
</tr>
</tbody>
</table>

S, Surgery; C, Chemotherapy; R, Radiotherapy; W, Working; SL, Sick Leave; *did not complete the diary.
Chapter 6

Diary Study

It was decided that a monthly diary would be sufficient. Other studies have utilised diaries that are completed over a 1-2 week period (Ong & Jinks, 2006); however, this would not have been appropriate for the current study. A monthly approach was better suited to the overall aim of this diary study; that is, to capture temporal fluctuations in perceptions of self-efficacy. The study period allowed rich data to be collected relating to different points of the cancer pathway, including diagnosis and how the treatment experience may change over time. The completion of diaries coincided appropriately with the questionnaire data collection time points. Figure 6.1 illustrates how diary completion coincided with questionnaire completion. The diary booklet largely comprised of prompts that sought to capture qualitative data. The diary booklet was comprised of three sections:

1) Section A was completed by all participants. First, participants were asked to write about the three most important events they had experienced over the past four weeks. This provided an indication of where the participant was in terms of their cancer journey. Second, as a measure of perceived self-efficacy participants were asked to describe how confident they felt about managing their illness, and to also rate their confidence level on a ten-point Likert scale (1 = not at all confident to 10 = totally confident). This item was taken from a commonly used chronic disease self-efficacy scale (Lorig et al., 1996). Finally, participants were asked to describe the activities they had carried out to manage their illness. This provided an outcome measure.

2) Section B was completed by participants that were in employment at the time when the diary booklet was completed. First, participants were asked to rate how confident they were in managing their work on a ten-point Likert scale (1 = not at all confident to 10 = totally confident). To gain insight into what, if anything, individuals were actively doing in order to manage their work, and how confident they were in doing so, participants were also asked to describe how confident they had felt about managing their work.
Figure 6.1: Diary study procedure within context of questionnaire study.
3) Section C was completed by participants who had stopped working, or were on sick-leave. To gain insight into perceptions about work, specifically, in relation to the possibility of returning to work, participants were asked about their return to work intentions. Finally, participants had the opportunity to write any further thoughts that they felt were relevant.

6.2.3. Procedure

The diary booklet (Appendix 8) was included in the questionnaire study pack, which was provided to all those expressing an interest in the study. Those wishing to take part in the diary study were asked to complete and return the booklet along with other questionnaire documentation. The first page of the diary booklet explained the purpose of the study and instructions for completion. To try and maintain a degree of consistency, participants were asked to complete the diary in a quiet environment at a similar time each month. Subsequent diaries were sent with a letter to participants approximately three and a half weeks after the date the prior diary booklet was completed. The enclosed letter requested participants to try and complete the diary on a particular date that coincided with the completion date of earlier diaries. The letter also allowed the researcher to maintain contact and build a rapport with participants, which may have helped prevent withdrawals over the study period.

To encourage participation for the entire duration of the study, participants were provided with stamped addressed envelopes in which to return completed diaries to the researcher. Upon receipt of each diary the researcher contacted the participant to thank them for taking the time to complete it. Participants were offered a copy of their completed diary at the end of the study such that they could reflect back over their experiences should they wish.
6.2.4. Analysis

The paper-based diary booklets were transcribed and organised according to participant and stored electronically. The data were analysed utilising a thematic analysis approach adopting the six phase process outlined by Braun and Clarke (2006). According to these researchers, thematic analysis provides core skills that are transferable to other qualitative methods. Some researchers suggest the coding process of thematic analysis is common to a number of qualitative methods (Ryan & Bernard, 2000); however, in spite of this, Braun and Clarke (2006) effectively argue, “thematic analysis should be considered a method in its own right” (p. 78). Thematic analysis is a widely used method that seeks to identify and analyse themes inherent in the data (Braun & Clarke, 2006). Boyatzis (1998) argues that thematic analysis goes further and can provide various insights into a particular research area. The usefulness of thematic analysis in the analysis of diary studies has been supported and demonstrated in the literature (Symon, 2004; Gordon, Prohaska, Gallant & Siminoff, 2007). Gordon et al. (2007) employed thematic analysis techniques to analyse qualitative aspects of a prospective diary that explored immunosuppression adherence among kidney transplant recipients. Due to the various thematic approaches used by researchers it is important to outline the specific nature of the approach that is being adopted here.

Thematic analysis was carried out on all data. Conducting the analysis in this manner allowed emerging themes to be analysed according to each time point, thus enabling temporal fluctuations and patterns to be analysed over the six month study period. Therefore, themes only apparent at certain time points could be extracted. First, the analysis process involved the researcher and an independent researcher systematically reviewing the diary transcripts separately. Second, initial ideas were noted, which guided preliminary codes. These codes were grouped into potential relevant themes and discussed between the researchers. Further analysis clarified the specific nature of each theme leading to the development of names for each theme. Subsequently, extracts were taken from the transcripts to exemplify each theme and reflected the overall experiences reported by participants. Consequently, results will be presented taking into account all completed diary booklets. Thus, temporal
fluctuations within and between themes will be discussed with an overall discussion at the end of the chapter.

6.3. Results

Four core themes were identified across time points, these are summarised in Table 6.2. These will be discussed in turn and particular attention will be paid to the temporal fluctuations within each theme.

Self-Efficacy and Cancer Self-Management

The majority of participants discussed their cancer diagnosis \((n = 6)\), including initial investigations (e.g. biopsy and colonoscopy) and the implications of disease stage upon their treatment. Within the sample, the role of self-efficacy in the management of cancer treatment, symptoms, fatigue, diet and exercise was diverse. At each time point participants were first asked to indicate on a scale ranging from 1 to 10 \((1 = \text{not at all confident} \text{ and } 10 = \text{totally confident})\) their perceived self-efficacy in their ability to do all the things necessary to manage their condition. Table 6.3 depicts the mean values and range of perceived self-efficacy scores according to each time point.
Table 6.2: Themes and sub-themes.

<table>
<thead>
<tr>
<th>Key Themes</th>
<th>Sub-Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self-Efficacy and Cancer Self-Management</strong></td>
<td>Treatment, Symptoms, Fatigue, Diet, Exercise, Psychological Well-Being, Normality and Self-Efficacy</td>
</tr>
<tr>
<td><strong>Self-Efficacy and Self-Management of Work</strong></td>
<td>Distraction and Normality, Work Adjustments, Self-Management and Work Ability</td>
</tr>
<tr>
<td><strong>Self-Efficacy and the Role of Support</strong></td>
<td>Family and Friends’ Support, Employer Support, Health Professionals’ Advice and Support</td>
</tr>
</tbody>
</table>
Table 6.3: Perceived self-efficacy in ability to self-manage cancer according to time point.

<table>
<thead>
<tr>
<th>Time Point</th>
<th>n</th>
<th>Mean ± SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline</td>
<td>10</td>
<td>8.10 ± 1.59</td>
<td>6 – 10</td>
</tr>
<tr>
<td>Time 1</td>
<td>8</td>
<td>8.75 ± 1.28</td>
<td>7 – 10</td>
</tr>
<tr>
<td>Time 2</td>
<td>7</td>
<td>8.71 ± 1.38</td>
<td>7 – 10</td>
</tr>
<tr>
<td>Time 3</td>
<td>6</td>
<td>8.83 ± 1.16</td>
<td>7 – 10</td>
</tr>
<tr>
<td>Time 4</td>
<td>6</td>
<td>8.67 ± 1.21</td>
<td>7 – 10</td>
</tr>
<tr>
<td>Time 5</td>
<td>6</td>
<td>8.17 ± 2.40</td>
<td>4 – 10</td>
</tr>
</tbody>
</table>

At baseline the mean self-efficacy score of 8.10 (SD = 1.59) suggests that participants possessed high levels of self-belief in their ability to manage their cancer. Figure 6.2 shows mean scores increased after baseline up until time 3 and these ranged between 7 and 10. However, beyond time 3, a decrement in self-efficacy was apparent at time 4 and 5. Nevertheless, the mean scores indicate that self-efficacy was relatively high and stable over time.

Figure 6.2: Mean (SD) self-efficacy in ability to self-manage cancer according to time point.
Chapter 6

Diary Study

*Treatment*

Treatment patterns varied within the sample (Table 6.1). At baseline, over two thirds of participants (\( n = 8 \)) acknowledged the treatment(s) they had received or were expecting to receive. A few discussed their surgery to remove the cancer and their recovery (\( n = 3 \)). Five participants specified that they were expecting to receive chemotherapy (either adjuvant or neo adjuvant) treatment. Reflecting on their own experiences, diagnosis and treatment seemed necessary for individuals to understand the nature and extent of their disease and with what they were faced. By doing so, participants felt they could start to consider the implications for them in terms of the management of their cancer. For instance, when one woman found out that her cancer had not spread this raised her perceived self-efficacy in her ability to manage:

*The cancer has not gone into my organs…Very confident because the cancer was caught early.*

Participant 5, baseline.

Another participant noted:

*Once I have been informed / learnt what is required of me, I have been confident and able to manage my illness and symptoms. It has been essential for me to have full understanding of matters to enable me to get fully prepared in better managing my illness.*

Participant 8, baseline.

Self-efficacy appeared to be important in understanding how participants were approaching their treatment pathway. Different patterns were observed, for example, a 56-year-old teacher described that he was confident about managing his treatment by approaching it in stages. He had undergone surgery and had adopted a ‘wait and see attitude’. In contrast, one participant was actively preparing herself for chemotherapy by ensuring that she could be as healthy as possible:

*I think I’m trying to get myself as healthy as I can for chemo, to try and put off any side effects, not sure whether this will work.*
Participant 7, baseline.

Recovery after surgery was mentioned by two participants at time 1. A female bank clerk described that the only thing that was preventing her resuming normality was the soreness. A male participant who had previously expressed that he was approaching his treatment in stages appeared to be pleased with the progress made particularly over times 1, 2 and 3. Furthermore, as a result this seemed to enhance his perceived self-efficacy in relation to managing his cancer:

*The progress has been remarkable and I am pleased with my growing independence...I have felt confident and this has grown as my recovery proceeds. Little advances each day indicate that my ‘illness’ will be overcome.*
Participant 1, time 1.

*Very good recovery from operation. Each day / each week has seen a very pleasing improvement.*
Participant 1, time 2.

*The surgery wound appears to have finally healed after 11 weeks. This is another ‘thing’ out of the way to help my movement forward.*
Participant 1, time 3.

For those receiving chemotherapy, successive diaries captured data on the management of treatment. When considering all seven participants undergoing chemotherapy, only one appeared to have a somewhat consistent experience temporally. Moreover, this 58-year-old female teacher’s entire cancer experience was somewhat set apart from the rest of the sample. When discussing her chemotherapy treatment this participant experienced few problems:

*I seem to still be doing well with everything. The chemo is going well.*
Participant 3, time 1.

*I seem to be tolerating chemo very well indeed.*
Participant 3, time 2.
However, for the remaining six participants chemotherapy treatment experiences fluctuated over time. Once treatment commenced these participants initially found it difficult to manage. For instance, in his third diary, a 56-year-old male felt his treatment dictated the activities that he could carry out. However, over time and after numerous treatment sessions, four of these participants noted how they eventually became familiar with their treatment (including side effects). For example, a 52-year-old retail assistant initially felt treatment had started well at time 1; however, at times 2 and 3 chemotherapy had become more difficult and therefore harder to manage. Despite early challenges, at time 5 this participant stated that she was more confident in her ability to manage treatment. Similarly, a 45-year-old teacher expressed that he felt very unconfident prior to starting treatment. However, modified treatment at time 2 led to improvements in self-efficacy beliefs:

*Much more confident now that they have reduced the dose (it was too much).*
Participant 4, time 2.

Alternatively, a 48-year-old charity fundraiser described how she experienced extreme highs and lows throughout her treatment. Furthermore, the manner in which treatment was administered resulted in problems managing it, which in turn may have negatively impacted her perceived self-efficacy:

*Time in between doses is so short which means that I seem to spend my life at the hospital...treatment is every other week - not much time to recover.*
Participant 2, time 4.

Such results indicate that participants needed time to familiarise / adjust to their chemotherapy treatment. This seemed a necessary process to learn how to manage their treatment. As a result, the nature of this experience may have influenced participants’ self-efficacy beliefs in their ability to manage their cancer and treatment.

*Symptoms*

When reflecting on their ability to manage their illness, at baseline, four participants described that they had not experienced any problems. One of
these individuals felt fortunate that no symptoms / side effects had presented themselves. Furthermore, another participant found it strange that no symptoms had surfaced, thus suggesting that they may have anticipated some side effects. Disease stage seemed important as one participant (44-year-old bank clerk) expressed confidence in her ability to manage her condition as the cancer was caught at an early stage. Other participants \((n = 3)\) were proactively engaging in forward planning behaviours to ensure that they were able to ward off and manage potential problems / symptoms, notably fatigue.

For example, a few participants acknowledged the need to rest and that this was something within their control and therefore indicative of high self-efficacy levels. For a 56-year-old teacher, this was a task that he had to perform and his self-belief in his ability to do so was evident as he was aware of what the consequences of not performing this behaviour would be:

\[
I \text{ make sure I have enough sleep to keep up my strength. If I don’t do this I look and feel unwell.} \\
\text{Participant 1, baseline.}
\]

Similarly, a 58-year-old teacher described how she was able to continue with tasks around the home; however, she had to pace herself throughout the day ensuring that she rested frequently. Engaging in such self-management behaviours seemed to produce positive outcomes:

\[
I’ve \text{ noticed that I’m getting stronger daily.} \\
\text{Participant 3, baseline.}
\]

In contrast, those possessing lower self-efficacy levels \((n = 3)\) at baseline appeared to report more symptom burden compared with those with more positive self-efficacy beliefs. A 57-year-old nurse was experiencing problems with abdominal and back pain. This individual’s feelings of low self-efficacy in her ability to manage her condition due to symptoms were exacerbated on work days. Interestingly, a male teacher illustrated how perceived self-efficacy varied according to the type of situation:
I have had problems with needing to visit the loo and the worry associated with timing of eating, not being able to find a loo (in time). A new experience making one feel set apart / or part of a different set, confidence in managing this was not high...Problems with walking and moving. I expect to improve to normality so this has been managed reasonably well and I felt reasonably confident.
Participant 4, baseline.

For the majority of participants, the presentation of symptoms altered over time, leading to changes in self-efficacy levels. When attempting to understand these experiences and temporal fluctuations in self-efficacy and symptom-management the nature and type of treatment was of key importance. For example, the participant (44-year-old female bank clerk) that received surgery alone reported minimal symptoms at time 1. Moreover, the information that this participant would be receiving surgery alone seemed to boost her self-efficacy beliefs to manage these symptoms knowing once they had passed her cancer would be overcome. In contrast, those receiving chemotherapy ($n = 8$) displayed different patterns over time. For example, a 47-year-old policy advisor reported that she was finding her treatment harder as it progressed. Similarly, as treatment progressed two other participants were managing diarrhoea, which for one woman was most prominent soon after a session of chemotherapy (58-year-old teacher, time 2). Such side effects did not appear to faze this participant especially in relation to her perceived ability to manage her treatment and symptoms. Two other participants had problems with constipation at time 4. Iron tablets were being taken by a 48-year-old woman to help alleviate the problem. At time 3, a 52-year-old retail assistant appeared to respond well to her hair thinning as it was expected:

Hair has started to thin, so this is another thing to deal with but I guess I prepared myself for this anyway so it isn’t really a major shock to me just dealing with it.
Participant 7, time 3.

At baseline and prior to chemotherapy, it was apparent that some participants were expecting certain symptoms / side effects to arise as a consequence of treatment. However, for two participants, both of whom were teachers, these anticipated symptoms were not experienced. Consequently, over the study
duration these participants also reported fewer symptoms, symptoms that did arise such as tingling and nausea were managed confidently as indicated by positive self-efficacy levels across all time points:

\[ I \text{ seem to still be doing well with everything. I do not seem to have any bad symptoms – the chemo is going well, I am eating well and sleeping well.} \]

Participant 3, time 1.

\[ I \text{ have been very lucky, I think because I am not getting any sickness or side effects.} \]

Participant 3, time 3.

\[ My \text{ symptoms have continued to be minimal and I’ve used gloves and bed socks to prevent tingling.} \]

Participant 3, time 5.

In contrast, symptoms experienced by two other participants led to temporally variable self-efficacy beliefs in relation to their cancer management (especially treatment). A charity fundraiser seemed to show lowest self-efficacy levels shortly after a chemotherapy session (time 3) and improvements the week proceeding treatment (time 5). Alternatively, at time 1 a 57-year-old nurse initially described how her confidence to manage her disease had increased since baseline. However, side effects such as nose bleeds and painful fingers at time 2 resulted in reduced confidence in treatment:

\[ Had \text{ bleeding nose and painful fingers so thinking if side effects get worse it will be difficult to cope generally this affects confidence with treatment.} \]

Participant 9, time 2.

At time 5, this participant’s self-efficacy levels seemed to be at her lowest due to the onset of pain:

\[ Not \text{ so confident as now getting a lot of pain...Spending longer in bed.} \]

Participant 9, time 5.
Fatigue

The most commonly reported symptom associated with chemotherapy was fatigue \((n = 6)\). The onset of fatigue for these participants was evident at either time 1 or time 2:

\[\text{Still get very tired.} \]
Participant 10, time 2.

Fatigue was perceived differently by participants:

\[\text{Chemo treatment started on 9th June. It has been a 'kind' regime with few side effects of any real consequence (some tiredness), just some 'inconveniences.'} \]
Participant 1, time 3.

\[\text{During recovery from chemo have found it difficult to focus and very lethargic.} \]
Participant 2, time 2.

For the female participant above who described chemotherapy related fatigue as problematic, it was clear that once these symptoms had diminished her self-efficacy beliefs in managing her cancer improved:

\[\text{However, when over the lethargy had bursts of energy and felt extremely positive and confident. Did lots of de-cluttering – very cathartic.} \]
Participant 2, time 2.

Other results suggest that symptoms of fatigue though initially problematic were better managed as time progressed. At time 4, a 48-year-old female acknowledged the need to rest; however, she found it frustrating as it was out of character for her to 'sit around'. Three participants were confident that they had learned when symptoms of fatigue would be most pronounced proceeding a chemotherapy session. Therefore, in response, they successfully engaged self-management behaviours such as taking rest when deemed appropriate. For instance, a 52-year-old part-time retail assistant acknowledged that her self-efficacy levels to manage her symptoms decreased between times 1 and 2 due to the onset of fatigue. However, by time 3 this participant was beginning to realise that rest was important prior to each chemotherapy session. Indeed, it
was reported that fatigue was most prominent a few days after treatment; hence, a routine was well in place to manage this. Alternatively, a 58-year-old teacher appeared to be aware of treatment-related fatigue and how to manage it as early as time 2. Furthermore, when compared with other participants, her high self-efficacy levels were evident early on and were consistent, thus enabled these behaviours to be maintained throughout:

*On about the Friday of the 1st week of treatment I tend to feel at my worst – more tired and needing to go to the loo more than normal. However, I just rest up on this day – watch rubbish on the television and sleep. By Saturday / Sunday I feel better and by the 2nd week I’m back to normal.*

Participant 3, time 2.

*I have continued to have confidence about managing my condition!...they (oncologist) are very pleased with my progress.*

Participant 3, time 5.

Similarly, at time 5 a 56-year-old male described how a routine was firmly in place that allowed him to respond to any symptoms that arose as a consequence of his treatment. Therefore, results suggest that such behaviours and positive outcomes strengthened self-efficacy beliefs to manage symptoms as treatment progressed:

*Very confident – as the weeks progress so does the ‘experience’ and how to deal with it.*

Participant 1, time 4.

*I’ve figured out what is best for me with my treatment. I really need to rest up before it. A few days after is when the tiredness kicks in, so I make sure I take it easy.*

Participant 7, time 3.

Further analysis of diaries over the study period found that a few participants referred to experiencing the cumulative effect of treatment (notably fatigue) as it progressed. A 56-year-old teacher showed that he was bearing in mind this cumulative effect and acknowledged that he was prepared and confident in his
ability to manage any changes as and when they may occur. This was also the case for the 58-year-old teacher who had previously acknowledged that she felt lucky where treatment was concerned and showed high self-efficacy levels throughout:

*I've had a great month and although I've been on my last lot of chemo with the cumulative effect of it all and do feel a little more tired at the end of the week that I've had chemo.*

Participant 3, time 4.

On the other hand, after five chemotherapy sessions one woman described how she was feeling ‘yuk’ for longer and that symptoms were also taking longer to wear off (time 4). As a result, this participant was left feeling as though she was ‘existing’ rather than living, which as a result seemed to negatively impact her self-efficacy beliefs.

*Diet*

In an attempt to manage their disease, the majority of participants ($n = 8$) had been monitoring their diet. This is something colorectal cancer patients are advised to do after surgery and during other treatment. At baseline, three participants altered their diet by reducing their food intake and consuming smaller portions. Two others expressed that their diet had always been healthy and balanced; however, they had been mindful to drink plenty of water and avoid foods that were not recommended. A 52-year-old retail assistant described how at times she found it a challenge to adhere to a diet plentiful of fruit and vegetables. For this woman, performing this management behaviour was part of a wider goal to prepare her for oncoming chemotherapy treatment. Alternatively, a female bank clerk stated that although she had not made any dietary changes, she had been eating more:

*Have not done anything different except eat more. I don't know if that is due to nerves or the illness.*

Participant 5, baseline.
It was increasingly apparent that over the study period maintaining a good diet was of importance to all participants that completed more than one diary \((n = 8)\). This was the case regardless of treatment type. For instance, at time 1 a 44-year-old female who received surgery alone stated that she was being mindful of what she consumed and was slowly re-introducing food into her diet. For the remaining eight who subsequently started chemotherapy treatment diet was monitored throughout. Early behaviours, such as eating a balanced diet set out at baseline were maintained by three participants. Two of these were teachers who seemed to have a healthy diet in place prior to the cancer. Therefore, this enabled the necessary changes to be made where appropriate with relative ease:

*I eat three regular meals a day. I try to eat small but healthy portions and I try to eat my main meal in the middle of the day as I think this is best for my condition in terms of digestion and so on.*  
Participant 3, time 1.

*I’ve managed my diet laid down in diary 5 and I feel I’m eating healthily but being careful about eating anything too spicy. My monthly meal with the girls described in diary 4 has been fine and I have enjoyed these as special treats.*  
Participant 3, time 5.

Temporal changes in self-management of diet were evident as a response to changing symptoms. Despite such monitoring behaviours, results suggest that self-efficacy beliefs in managing diet varied. For example, at time 1, a 47-year-old policy advisor described how she was finding it difficult to manage her diet around her stoma appliance (unable to eat fruit and vegetables). Similarly, a 57-year-old nurse who had to pulverise her food reported that she did not feel confident about maintaining her weight and iron levels as she was not eating or enjoying her food. Alternatively, at time 2, a 48-year-old appeared to be doing well at managing to eat smaller meals. Further to this, this participant was concerned about possible weight gain as she had been prescribed steroids. Diary entries at time 4 and time 5 suggest that high self-efficacy levels enabled this participant to monitor and adjust her diet as new challenges arose over time:
Had to watch diet – include more fibre and fruit because of taking iron tablets which cause constipation.
Participant 2, time 4.

Because of my weight increase – due to steroids I have been very careful with my diet.
Participant 2, time 5.

Exercise

Being able to exercise was important to five participants. At baseline, three participants mentioned that they had attempted to exercise as much as they could. Therefore, suggesting it was important to them and still within their capability. A 56-year-old teacher stated that regular exercise helped him to keep in shape and ‘feel’ fit. A female nurse awaiting chemotherapy treatment exercised at a lower intensity which enabled her to continue with her main leisure activity. After surgery, a 45-year-old male teacher seemed to perform beyond his own perceived self-efficacy beliefs:

Enjoying a challenging walk and completing it within a time above all expectations.
Participant 4, baseline.

By time 1, due to treatment effects, these two male participants had to alter their activities as they were no longer able to exercise in the same manner. For example, the 45-year-old teacher was participating in more sedentary activities that ‘suited the brain rather than the body’ such as painting and writing. Alternatively, the 56-year-old teacher continued to make the effort to exercise to build up his strength, in turn this may have boosted this individual’s self-efficacy beliefs, hence reinforced this behaviour:

As far as activities are concerned I am building up my strength as I recover.
Short strolls are turning into longer ones, albeit in the garden.
Participant 1, time 1.

Two other female participants revealed efforts to exercise in their final diaries (time 5). In particular, chemotherapy treatment and side effects may have
prevented one of these participants from taking part in exercise earlier. This 48-year-old charity fundraiser appeared to be attempting to do more in terms of exercise and diet management in response to weight gain associated with medication (steroids):

Because of my weight increase due to steroids I have been very careful with my diet. I'm also trying to do more exercise but only gentle exercise – walking, wearing a pedometer and endeavouring to achieve 10,000 steps a day. Some days I achieve 12,000 and others only 6,000 or 8,000.

Participant 2, time 5.

Overall, both treatment and the associated side effects did seem to impact ability to exercise over the study duration. However, for participants whose routine comprised of exercise prior to cancer it was apparent that they were confident in their ability to judge and subsequently amend their activities where necessary. In addition, other participants \((n = 2)\) were confidently able to engage in activities as a response to problems associated with their cancer treatment.

**Psychological Well-Being**

A few participants attempted to adopt a positive outlook at baseline. A 48-year-old charity fundraiser stated that after overcoming the initial shock of diagnosis she was trying to remain positive. This was also the case for a female nurse. Alternatively, despite feeling positive a 56-year-old teacher mentioned that he had to amend tasks to reduce emotional pressure. Subsequent diaries suggest temporal fluctuations in psychological well-being that appeared to be associated with the onset and experience of chemotherapy treatment. Four participants exhibited changes in their psychological outlook. For instance, a 57-year-old nurse found her ability to cope challenged by the onset of side effects at time 2. Therefore, initial attempts to remain positive seemed threatened by fears of more side effects surfacing in the future. Consequently, self-efficacy beliefs may have been negatively impacted. The most prominent temporal fluctuations in psychological well-being were apparent for the female charity fundraiser. At time points 2 and 3, this woman reported feelings of extreme highs and lows.
Further analysis of time 3 data indicated that psychological well-being improved once she was over her session of chemotherapy. Time 4 results suggest the cumulative effect of treatment led to an adverse impact on well-being, hence perceived self-efficacy levels:

*The last few weeks I have felt more despondent and tearful. Not really sure why. It seems like I am existing rather than living and my life is on ‘hold.’ Also side effects are taking much longer to wear off.*
Participant 2, time 4.

Encouragingly, at time 5 this participant revealed that she felt more positive and was generally coping well. Meanwhile, compared with baseline, a 45-year-old male teacher seemed to be veering towards the opposing end of the spectrum:

*A retrospective look at my life’s achievements – failures – experiences, desperately wanting to spend time with family…I was already in a bad ‘life position’ and felt pretty unhappy about my life position, achievements etc.*
Participant 4, time 1.

*I do have a strange feeling of having the ‘sword of Damacles’ hanging over my head though – something maybe I should get counselling for – the opposite of what one might expect – not indestructible (although I do feel I have 9 lives!) but that I will die in a car crash. I hope it is not prophetic.*
Participant 4, time 2.

In contrast, the psychological well-being of a 56-year-old male teacher and a 58-year-old female teacher seemed to be more consistent. Moreover, at time 1 the presence of support appeared to impact psychological well-being favourably. Therefore, this positive outlook may have led to enhanced self-efficacy beliefs:

*I am still feeling very positive as I’m feeling good and having good experiences as I’ve mentioned already. I think that all of this really helps.*
Participant 3, time 1.

*The enormous support from family and friends has been uplifting.*
Participant 1, time 1.
Such results indicate that psychological well-being may impact self-efficacy. Broadly speaking, those with a better psychological outlook appeared to have higher levels of self-efficacy. Hence, in turn this may lead to better self-management behaviours thus outcomes.

**Normality and Self-Efficacy**

In terms of cancer management, efforts to resume normality were important for some. In particular, those with higher perceived self-efficacy beliefs in their ability to self-manage their disease appeared to find this easier when compared with those with lower perceived self-efficacy levels. At baseline, five participants discussed normal activities that they had taken part in. This resumption of normality served different purposes. For one participant, a 56-year-old male teacher, focusing on other things such as work and family were helpful distractions from the disease. Others placed importance on the fact that they had resumed activities such as attending a friend’s wedding or going on holiday. A 58-year-old female stated she had been able to go on a regular girls’ night out, which she has done on a monthly basis for many years. The same lady, a teacher, had been abroad to visit family, this seemed possible due to her perceived high self-efficacy beliefs in her ability to manage whilst away:

> I managed to go to see my son, daughter-in-law and new baby granddaughter in Berlin at the end of August…I felt very well while there.

Participant 3, baseline.

Efforts to continue as normal appeared to fluctuate temporally for all but one participant. When discussing the most important events to occur during each diary entry, this 58-year-old teacher consistently reported that she had participated in various ‘normal’ activities, such as, visiting family abroad (baseline), theatre trips and having a new kitchen fitted (time 2), weekends away and Christmas shopping (times 3 and 4). Besides, this participant’s perceived self-efficacy beliefs were invariable across diary entries (rated as 10), thus suggesting that being able to maintain a degree of normality in the face of cancer may have reinforced self-efficacy beliefs in her ability to manage her cancer. Similarly, a 45-year-old male teacher who had just started
Chapter 6

Diary Study

Chemotherapy mentioned his efforts to regain normality at time 1, soon after surgery. Other participants (n = 4) exhibited varying patterns. It was noted that during the first three diary entries two females (a charity fundraiser and a retail assistant) who had both undergone surgery and started chemotherapy appeared to be more focused on rest and recovery. Indeed, it was not until times 3 and 4 when more normal activities were resumed. Even though normal activity was resumed it was compromised for one participant due to factors associated with the disease:

We were all disappointed at having to cancel our holiday in the sun to Portugal but it was definitely the right decision since I had to go to the local hospital whilst away because I was losing blood.
Participant 2, time 4.

Self-Efficacy and Return to Work Intentions

Intentions to return to work were expressed by participants who were all on sick leave at some point over the study duration. Some were more vehement in their desire to return to work than others:

Although currently I am on ‘sick leave’ from work, I think it is worth reiterating that I wish to return to work...
Participant 8, baseline.

However, the strength of these intentions varied within the sample due to fluctuations in self-management of treatment and symptoms that led to changes in self-efficacy. Furthermore, symptoms (particularly chemotherapy side effects) appeared to lead to decrements in perceived work ability. Therefore, it was apparent that certain factors were important when attempting to understand return to work intentions.

The Impact of Treatment, Symptoms and Self-Management Skills

Self-efficacy and return to work intentions seemed to be influenced by treatment, the experience of symptoms such as fatigue and overall self-management skills. At baseline, even though three participants wanted to
return to work, they could not plan when this would be possible as they were either expecting to receive chemotherapy or unaware of any further treatment they may receive. A 48-year-old charity fundraiser wanted to return to work but did not know when this would be possible. In addition, at baseline, she was focused on recuperating after the operation, which she found frustrating. Furthermore, she was awaiting an outpatient’s appointment to discuss subsequent treatment that may be necessary. For some, focusing on treatment took precedence over return to work intent:

Would definitely want to go back to work at some point, but at the moment I can’t really plan when this might be possible. At the moment I need to deal with the chemo and see how I go with that before I figure out what to do about work.
Participant 7, baseline.

Therefore, subsequent diaries identified that time taken to begin chemotherapy was a factor that seemed to impact return to work intentions. Four participants (females; n = 3), started chemotherapy at follow up time 1. In contrast, a 52-year-old nurse started her treatment by time 2 and a 56-year-old teacher by time 3. Consequently, treatment (both surgery and chemotherapy) appeared to be a barrier to return to work. This is supported further by the experiences reported by a 58-year-old teacher. In spite of consistently expressing a desire to return to work and exhibiting high self-efficacy beliefs throughout the study, this participant’s return to work was delayed. This was due to her employer’s policy stating that at least three months leave was necessary after major abdominal surgery. Hence, treatment as a barrier preventing return to work was also evident in those whose self-management skills were positive. In spite of this, this participant’s high self-efficacy beliefs and self-management skills enabled her to negotiate work to do from home, such as marking and lesson plans for her examination classes:

I feel that although I’m on sick leave at present due to having had the operation and not being able to return until 3 months has passed...However, I have prepared schemes of work, lesson plans and marked and set coursework for all of my exam classes.
Participant 3, time 1.
Further results after baseline suggest that treatment and the associated symptoms seemingly continued to exert an influence upon return to work intentions. A 45-year-old male teacher described that he could not consider returning to work until his treatment was relatively stable. At time 2, a reduced dose resulted in a degree of stability which in turn enabled this participant to eventually return to work. However, for others, the unpredictable nature of treatment and symptoms led to changes in return to work intent. For example, a nurse who had started chemotherapy at time 2 had no intentions to return to work due to not knowing how she would feel on a day-to-day basis. The onset of more troublesome symptoms such as sore fingers and fatigue also led to this participant admitting that she had no intentions to go back to work at time 4; and by time 5 she had decided that she would not return to work:

_Had some very difficult days with sore mouth...difficult to talk or swallow...sore feet and blisters, difficult walking some days...No intentions to return to work...Chemotherapy side effects...would not feel safe to practice._

Participant 9, time 4.

_No, don’t feel safe to practice. Accepted for ill-health retirement._

Participant 9, time 5.

Two female participants, one a charity fundraiser and the other a retail assistant, were only in a position to plan possible return to work at times 3 and 4. This appeared to be due to improved self-efficacy in self-management skills that appeared to ensue as a result of adjusting to their chemotherapy treatment and the associated symptoms. Thus, as time passed, treatment and symptoms were becoming less of a barrier. However, although return to work intentions were evident and further strengthened once treatment was not viewed as a barrier (to a lesser degree); these women felt that realistically they could only consider returning to work upon completion of chemotherapy treatment (beyond study time frame):

_Yes hoping to return after chemo sessions completed– probably after Xmas._

Participant 2, time 3.
Similarly, a 56-year-old male teacher who had withdrawn from work at time 1 stated that returning to work was dependent on future diagnosis and treatment. Furthermore, even though this participant expressed intentions to return to work throughout time points 1 to 5, he acknowledged that ultimately the matter may be out of his control:

\[ I \text{ am also being realistic and I might find that circumstances dictate a delayed return to work or, indeed early retirement.} \]
Participant 1, time 1.

\[ I \text{ am thinking about returning to work. However, this will depend on my chemo and further operation. I am not ready to ‘finish’ / retire although I am in a position to do so.} \]
Participant 1, time 2.

\[ I \text{ have to make a major decision as alluded to earlier. I may not be able to return, because of chemo, until Jan 09. I have been asked to consider early retirement based on ill-health.} \]
Participant 1, time 4.

By time 5, despite the submission that this participant would be returning to work for a short period of two weeks, he intended to apply for early retirement on health grounds due to an impending operation and further chemotherapy treatment. Despite this, he stated that he intended to consider other options such as voluntary work in the future, suggesting that self-efficacy beliefs in ability to work were still promising albeit to a new job type:

\[ I \text{ intend to apply for early retirement on health grounds...At my age 56 I feel it may be the right time to reflect on my work/life balance to return to an exhausting job after so much treatment may be too much to handle. Instead I think other ‘alternatives’ will prove more attractive: voluntary work, training to become a magistrate for example.} \]
Participant 1, time 5.

Consequently, even though some participants intended to return to work and had positive return to work self-efficacy beliefs, treatment, symptoms and
overall self-management skills served as barriers preventing a return to the workplace. Moreover, results suggest such barriers may have been most prominent early on during treatment when symptoms seemed more problematic.

**Self-Efficacy, Attitude and Self-Management Skills**

Attitudes towards work coupled with perceived self-efficacy and self-management were also important when considering return to work intentions. Being able to work served as a marker of normality for all. One 44-year-old male wanted to return to work, thus, normality as soon as it was practically possible. However, as outlined in earlier results the impact of treatment and self-management of symptoms seemed superior to actual return to work intentions. Similarly, a male teacher (45 years) wanted to re-immers himself in his work as it provided an atmosphere and degree of discipline. Further to this, a few participants saw work as something that enabled them to function effectively (n = 5). For example, a charity fundraiser expressed that work was necessary for stimulation and self-preservation. Since having to take time to recover a part-time retail assistant appeared to show a greater appreciation of work:

*We all moan about work, but when it comes to sitting about at home I know I couldn't put up with it for long! Your brain starts to feel a bit fuzzy!*

Participant 7, baseline.

Attitudes towards work were discussed in further diaries, particularly for one participant who felt a return to work was the outcome she was striving for as it would help her and her family move forward from the cancer. Moreover, having a hectic life seemed to be the favoured environment for this participant to perform well. Additionally, this charity fundraiser’s high self-efficacy beliefs and return to work intentions appeared to be clouded by her treatment, in particular, she was finding the need to rest whilst undergoing chemotherapy problematic:
Chapter 6

Diary Study

I’m aiming for a return to work after Christmas – I need to get back into the world of work. I hate not being able to lead my normal hectic life. Juggling is an art I’ve managed to master.
Participants 2, time 5.

With time it seemed that although work was an important aspect of their lives some participants (n = 4) were considering the implications of their cancer in a more realistic manner. These participants (three females) appeared to show a shift in attitude by acknowledging the need to recognise the best way to manage and balance their health, well-being and work. Similarly, at time 3, a 56-year-old male teacher found the prospect of not teaching again ‘unsettling’ after he had been asked to consider ill-health / early retirement. However, this participant’s final diary suggests that this was something he had come to accept but did not see this as the end of his working life. Instead, he showed that he felt he was more than capable (i.e. high self-efficacy beliefs) of turning his attention and skills to something new. This change of direction and re-evaluation of work was also apparent for a 45-year-old male teacher. This participant stated that he was attempting to build a new sense of purpose via charity work he was participating in at time 2. Such work was found to be rewarding as it felt as though he was doing something that was more purposeful and effective. Hence, suggesting that in light of a cancer diagnosis and the experience of treatment the meaning of work and its importance may have changed for some.

Self-Efficacy and Self-Management of Work

Section B of the diary was completed by participants who were working when the diary was completed. In total, six participants completed this section as they were working at some point during the study. At baseline, a 56-year-old male teacher, a 44-year-old female bank clerk, a 57-year-old female nurse and a 47-year-old policy advisor continued to work after being diagnosed with colorectal cancer. However, at time 1 all but one of these participants (participant 10) had to leave work due to the commencement of chemotherapy treatment. Subsequent time points showed that three participants (58-year-old female teacher and 45-year-old male teacher) two of whom were on sick leave
at baseline had managed to return to work at time 2. First, participants were asked to rate on a scale ranging from 1 to 10 (1 = not at all confident and 10 = totally confident) their perceived self-efficacy to do all the things necessary to manage their work. Table 6.4 depicts mean perceived job self-efficacy values according to time point. Mean values at baseline (8.50; SD = 1.91) and time 1 (9.00) show a small increment in perceived job self-efficacy (Figure 6.3). When compared with baseline, all time points suggest high perceptions of job self-efficacy. The only decrement was observed between time points 1 and 2, however, only one participant was working at time 1. Despite only two participants (58-year-old female teacher and 47-year-old policy advisor) working at times 3, 4 and 5, mean values suggest an improvement in perceived job self-efficacy. Of all participants working at baseline, two rated their self-efficacy highly, with the maximum score of ten. In contrast, one woman felt less able to manage her work, rating her self-efficacy as six.

Table 6.4: Perceived self-efficacy in ability to self-manage work according to time point.

<table>
<thead>
<tr>
<th>Time Point</th>
<th>n</th>
<th>Mean ± SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline</td>
<td>4</td>
<td>8.50 ± 1.91</td>
<td>6 - 10</td>
</tr>
<tr>
<td>Time 1</td>
<td>1</td>
<td>9.00</td>
<td>9</td>
</tr>
<tr>
<td>Time 2</td>
<td>3</td>
<td>8.66 ± 0.58</td>
<td>8 - 9</td>
</tr>
<tr>
<td>Time 3</td>
<td>2</td>
<td>9.00 ± 0.00</td>
<td>9</td>
</tr>
<tr>
<td>Time 4</td>
<td>2</td>
<td>9.50 ± 0.71</td>
<td>9 - 10</td>
</tr>
<tr>
<td>Time 5</td>
<td>2</td>
<td>10.00 ± 0.00</td>
<td>10</td>
</tr>
</tbody>
</table>
Different patterns of return to work and changes were seen amongst the six participants who were working at some point over the course of the study. Only one participant managed to work throughout the entire study duration (participant 10). Results suggest that these individuals continued / returned to work because it served as a distraction and marker of normality. In addition, work adjustments that were offered and implemented by employers also appeared to facilitate work outcomes; in particular, for two participants who returned to work whilst undergoing chemotherapy treatment.

**Distraction and Normality**

All six participants viewed work as a welcome distraction from their cancer. Moreover, it served as a marker of normality. A 44-year-old bank clerk described how being able to work made her feel as though she was leading a normal life. However, in the same baseline diary this participant’s transition from working to taking sick leave due to surgery became apparent. She expressed that her last day at work was emotional. This may have been because work was previously a distraction from the cancer, hence, the absence of this distraction may have forced her to acknowledge and confront the cancer that she was faced with. Another 56-year-old male teacher further described that being able to work may have enhanced his coping skills:
It has given my week(s) structure and a clear purpose and I think it has helped me cope with the spectre of cancer that lurks in the mind.

Participant 1, baseline.

Similarly, an appreciation for work was evident for the two participants who returned to work at time two. The 45-year-old teacher was pleased that things were returning to normal. Meanwhile, the high-self-efficacy beliefs of a 58-year-old teacher seemed to reinforce her desire to return to work. Furthermore, effective self-management skills (e.g. treatment management) that appeared to be associated with fewer symptoms seemed to lead to enhanced self-efficacy, thus, a drive to resume normality as early as possible:

I seem to be tolerating the chemo very well indeed…I listen to my body and rest when I need to. I seem to be managing the symptoms well…I returned to partial work on 10/11/08 and I’m thoroughly enjoying it. Pupils and staff are totally supportive and I’m feeling that things are returning to normal.

Participant 3, time 2.

Work Adjustments, Self-Management and Work Ability

At baseline, three of the four participants that were working described work adjustments had been made, for example, a longer lunch break and more sitting. Such changes were implemented to address symptoms of fatigue. However, the most prominent adjustment made related to the number of hours worked (i.e. reduced hours). A 47-year-old policy advisor who worked throughout described how she worked fewer hours each day. Meanwhile, a 56-year-old teacher described how his phased return to work comprising of fewer hours enabled him to manage his work commitments and recovery (i.e. rest periods) in a satisfactory manner, which in turn appeared to help him psychosocially:

It has allowed me to carry out work related tasks e.g. marking, preparation and administration without being under too much pressure both physically and emotionally.

Participant 1, baseline.
In spite of this, this participant had to withdraw from the workplace at time 1 as chemotherapy treatment and symptoms such as fatigue became a barrier that prevented him from being able to continue with work. Furthermore, this barrier was present even though this participant consistently showed high self-efficacy beliefs in relation to his self-management skills:

Careful monitoring of diet to make sure it meets my needs – balanced and giving me the energy levels to cope with chemo...Treatment tends to dictate my activities but I am trying to keep myself occupied to avoid boredom and dwelling on my 'situation.'

Participant 1, time 3.

The introduction of work adjustments suggests that decrements in perceived work ability were inherent within the sample. This was even the case for the 47-year-old female who worked throughout:

Still get very tired...Working slightly less hours than normal and doing some work from home.

Participant 10, time 2.

However, by time 5 this participant's work ability appeared to have improved:

No problems at all – back to full strength...No adjustments necessary.

Participant 10, time 5.

A 45-year-old teacher who was on sick leave at baseline returned to work at time 2. This was because this participant felt that his treatment had become more stable. However, he was only able to do half a day supply teaching each week as it was all he could manage. Moreover, it appeared that problems with fatigue arising during the afternoon may have prevented him from being able to work more hours:

Returned to half a day a week of supply teaching although wearing – not as tiring as before. I find myself ‘power napping’ a new phenomena. Tiredness comes on fast in the pm – but half an hour’s nap sorts it out well.

Participant 4, time 2.
Similarly, for a 57-year-old nurse, work adjustments appeared to be in place to combat decrements in perceived work ability. This participant exhibited lower perceived self-efficacy beliefs about managing her work when compared with her pre-cancer work ability. In particular, the woman explained that she had to finish work early to manage symptoms of fatigue that surfaced during the afternoon, hence these symptoms negatively impacted work ability at baseline. Time 2 results for this participant suggest that decrements in self-efficacy due to a reduction in perceived self-management skills (i.e. poorer symptom management) resulted in reduced work ability that eventually led to this participant leaving work:

_Tired by afternoon so finishing 1½ hours earlier than usual._
Participant 9, baseline.

_No (intentions to return to work). My work consists of seeing patients with appointments. Unable to fix definite days as chemotherapy at short notice...Tired._
Participant 9, time 2.

The two participants (both teachers) that returned to work at time 2 also described how they had reduced their hours. One of these provided details of her partial return to work that had been implemented because of her positive self-efficacy beliefs in managing her work and her cancer. Being able to carry out work tasks from home was also helpful:

_Going back to work part-time. I’ve returned to school for my exam classes. (oncologist’s name) said that he’d be guided by me and as I’ve felt well enough I’ve embarked on a partial return to work...I prepare work at home and my marking here also._
Participant 3, time 2.

_I am only going in for my exam classes so if I have an 8.45 hour lesson followed by an 11.25 hour lesson, I come home in between (only 1.7 miles away). My second in department has taken on some of my Head of Department duties._
Participant 3, time 3.
I continue to work 13 out of the 20 lessons I would be doing when working full-time and this is going very well.
Participant 3, time 4.

Self-Efficacy, Self-Management and Perceptions of Work Ability

Perceptions of work ability were discussed by all participants at some point during the study. The subject was touched upon by participants who were able to work at some point over the study duration. In contrast, for those who were on sick leave, work ability was discussed as a barrier preventing return to work even in the presence of high return to work intent. Those who were working at baseline (n = 4) felt unable to perform in the same manner prior to colorectal cancer. In response to diminished work ability, three of these individuals reduced their hours to deal with symptoms of fatigue or to avoid undue physical pressure. For one of these participants, decrements in physical work ability led to diminished self-efficacy levels whilst at work, however, mental work ability was not impaired:

Not so confident as before (at work). Tired by afternoon so finishing 1½ hours earlier than usual. No problems with tasks able to concentrate on work which keeps my mind off illness... Reduced hours. More relaxing lunch break. More sitting.
Participant 9, baseline.

For those not working (n = 6), differences in work ability were evident at baseline. For example, a 51-year-old female rental car assistant who was awaiting another operation (stoma appliance reversal) was considering returning to work on a part-time basis, as she felt that her current work ability was impaired when compared with her prior capabilities. However, being able to do so was contingent upon whether her employer would allow it. Three others anticipated that treatment effects may impact work ability, even though they expressed a desire to return to work. Alternatively, others (n = 3) seemed to exhibit high levels of self-efficacy in their work ability; one participant had managed to continue with some work whilst officially on sick leave:
I feel well and am eager to return to work...I’ve prepared lesson plans for my exam classes until Christmas.

Participant 3, baseline.

Further diaries showed that changes in perceived work ability seemed to be largely associated with treatment effects. Due to surgery, a 44-year-old bank clerk was unable to sit for long periods of time. This therefore prevented her from returning to work as her job involved her sitting for long periods of time. However, this participant was aware that this was a temporary issue. Six of the seven participants that completed more than one diary showed differences in perceived work ability over time. These changes appeared to be associated with chemotherapy treatment. For example, at baseline a nurse who was awaiting chemotherapy treatment was able to work. However, at 1 she was on sick leave as she felt unable to perform her job as her treatment led to unpredictable symptoms that in turn led to decrements in her perceived work ability. At time 2, symptoms worsened and the cancellation of treatment impacted this participant’s work ability further. As a result, she showed lower levels of self-efficacy in her ability to return to work:

Some days feel well and think I could go to work.

Participant 9, time 1.

My work consists of seeing patients with appointments. Unable to fix definite days as chemotherapy at short notice. Difficult to concentrate. Sore fingers unable to handle certain items or write properly. Tired.

Participant 9, time 2.

Two participants, both teachers, had managed to embark upon a return to work at time 2. However, the nature of their return suggested that their perceived work ability differed. A 45-year-old male had returned to half a day of supply teaching as this was deemed manageable in relation to his treatment and symptoms of fatigue. This participant admitted that in time he was confident that he would be able to increase his hours if required. Hence, suggesting that he felt that his work ability would improve over time as he made a full recovery. Another 58-year-old teacher also believed that once treatment was completed
she would make a full recovery, thus in turn her work ability would gradually improve and be comparable with pre-cancer levels. This teacher had returned to work partially (13 / 20 classes only) whilst undergoing treatment, hence indicating that treatment impacted work ability. It was apparent from successive diaries that this participant was gradually increasing her workload in response to perceived work ability increments that resulted from her effective self-management skills. Consequently, results infer that high self-efficacy beliefs displayed in relation to managing her work and cancer strengthened over time, which may have led to such positive work outcomes:

*I have continued to have confidence about managing my condition! My symptoms have continued to be minimal and I've used gloves and bed socks to prevent tingling. I've managed my diet laid down in diary 5 and I feel I'm eating healthily but being careful about eating anything too spicy...I continue to work for 13 out of the 20 lessons I would be doing when working full-time and this is going very very well!*  
Participant 3, time 5.

Therefore, within the sample it appears that self-efficacy beliefs in ability to manage treatment effects may have impacted perceptions of work ability, hence return to work intentions. Those who experienced more symptoms and / or seemed unsure about how to manage them in the context of their work were unsure about when they could return to work. Alternatively, those such as the two teachers who did return to work showed that they were in a position to confidently manage their symptoms, thus had better perceived work ability and therefore returned to work.

**Self-Efficacy and the Role of Support**

The nature of social support received was described by all participants at baseline. Of the seven participants who completed more than one diary, the majority (n = 6) consistently mentioned support received which was particularly important when attempting to understand participants’ self-efficacy beliefs. Moreover, such support was provided by various sources, including family and friends, health professionals and employers. Reflecting on these social support
networks suggested that they were immensely valued by most of the sample. Furthermore, the results suggest the role of support appears to be important in relation to self-efficacy beliefs and intentions to return to work and perhaps even perceived work ability.

*Family and Friends’ Support*

The majority ($n = 5$) of participants described how they had drawn upon support from their network of family and friends at baseline. In particular, one participant described the relief he and his wife felt after informing close family and friends of his cancer. The potential benefit of such support upon perceived self-efficacy in relation to self-management was also apparent:

> *Their support has been invaluable and made us feel very positive as to what the future holds.*

Participant 1, baseline.

Such support was sustained and evident in subsequent diary entries. Four participants touched upon how support from family and friends had enabled them to feel positive. A part-time retail assistant felt that support from family members helped her self-management during chemotherapy at time 3 as this was when her energy levels were lowest. This was also the case for a 48-year-old female charity fundraiser who found chemotherapy challenging at time 5:

> *Night before chemo I feel very low and question whether I should proceed with the course because I know the pattern by Friday I will feel Yuck! Generally I’m very positive and able to cope well. I have a wonderful family and fantastic friends who have been so supportive.*

Participant 2, time 5.

For two participants, both teachers, such positive support networks appeared to enhance self-efficacy beliefs favourably. For example, the 58-year-old female teacher found her friends accompanying her to chemotherapy sessions and other appointments helpful, even though she felt able to attend them alone (time 3). Similarly, the 56-year-old male teacher described how such support helped him to feel confident. Additionally, the presence of a positive support network
appeared to be associated with more favourable return to work intentions and self-efficacy beliefs. More importantly, for these two teachers the presence of support from various sources may have buffered the negative impact of chemotherapy treatment and symptoms by enhancing self-efficacy beliefs and self-management skills:

Very confident (managing cancer) with help of family, medical staff and friends.
Participant 1, time 3.

The role of support in relation to the management and maintenance of a good diet and help with household tasks became more important to five participants as treatment progressed:

At home, my husband retired at Christmas so he keeps many of the household tasks done by hovering through, tidying up...as well as doing most of the cooking which he really enjoys. This just leaves me with washing, drying and ironing clothes...We’re a good team and I really enjoy keeping my house the way I want it and he really helps.
Participant 3, time 3.

My routine has been in place from the start and I’ve stuck to it pretty well. Family have had to help a bit more especially week of chemo because that is when my energy levels are worst. Their support has really helped.
Participant 7, time 3.

Therefore, the role of support from family and friends appeared to enhance self-efficacy beliefs over time. Results indicate that those with a supportive environment such as help with household chores and diet were confident in their cancer self-management skills. As a result, these participants, especially the two teachers (58-year-old female and 56-year-old male) consistently expressed intentions to return to work.

Employer Support

The level of support received from their employer was touched upon by seven participants at baseline. Those receiving positive levels of support commented
upon the reactions of colleagues. For instance, one participant wanted to show thanks and respect to those at work for being very decent in their reaction. As a response to this, one of the reasons for him wanting to return to work as a teacher was due to an obligation he felt to honour his contract commitment:

\[\text{I am on sick leave and would like to return: to honour my contract commitment.}\]

Participant 4, baseline.

Three others acknowledged that it was due to a supportive employer who made work adjustments such as reduced hours or a phased return to work, which enabled them to continue to work. Alternatively, a female teacher on sick leave (at baseline) stated that she had been able to liaise with school to prepare and mark work for her exam classes. In this case it seemed that this individual’s high perceived self-efficacy enabled her to continue with such tasks and may have been noticed and thus facilitated by her employer:

\[\text{I’ve continued to set work and mark all of my examination classes’ work. I’m in regular contact with my second in department and she checks things out with me on a regular basis...My head is more than prepared to bring in a phased return to work until all of my treatment is finished.}\]

Participant 3, time 2.

The role of employer support also seemed important when attempting to understand two participants’ return to work intentions. For example, a 47-year-old senior manager who was awaiting further treatment hoping to return to work stated that he felt he would be fully supported in this by his employer. Conversely, another participant who worked full-time prior to diagnosis was contemplating returning to work on a part-time basis but was unsure whether her employer would be supportive:

\[\text{I may go back to work on a part-time basis if allowed, by my employer.}\]

Participant 6, baseline.

Support from employers and colleagues was received throughout the study by five participants. At the most basic level these participants felt supported when employers maintained contact whilst they were on sick leave. For instance, a
58-year-old teacher on sick leave at time 1 mentioned that being in constant contact with her colleagues and head teacher made her feel well supported. A charity fundraiser who was keen to get back to work disclosed that her employer allowed her to do what she could (from home) although officially on sick leave. Such support may have benefited her sense of self-worth and self-esteem:

*Officially I am on sick leave – doctor’s notes submitted, but I have negotiated with my manager what I can do if and when I feel well enough. This makes me feel useful and still in touch with the ‘real world.’ This agreement is very flexible and regularly reviewed.*

Participant 2, time 2.

Three female participants’ experiences showed how the nature of employer support changed according to the stage of treatment (and overall cancer journey). As treatment progressed, it was apparent that these individuals were beginning to consider when they could possibly return to work. Consequently, in response to this their employers suggested possible work adjustments that could be introduced to aid their return to work process. Such advice was provided as early as time 1 for a 58-year-old teacher, who subsequently had embarked upon a phased return to work at time 2. Even though this participant possessed high return to work self-efficacy beliefs, it seemed that having to undergo chemotherapy treatment resulted in a partial return in the first instance:

*I have to return to a partial return to work in late November, for exam classes while still on chemo. I hope to return full-time in February after chemo.*

Participant 3, time 1.

The importance of support upon self-efficacy in relation to ability to return to work was apparent for a retail assistant who had received surgery and was undergoing chemotherapy. At time 2 this participant envisioned that she may encounter problems returning to her role that involved being on her feet and on the shop floor throughout her shift. Therefore, suggesting this participant’s levels of perceived self-efficacy in her ability to perform her job had decreased. In contrast, at time 3 increased levels of employer support in the form of work
adjustments seemed to lead to improvement in return to work self-efficacy beliefs:

*My manager has been in touch and said that I can work in the office for a bit if I want. This would be great because I know I would find going back on the shop floor too much. So this is an option in a couple of months or so. I've always worked part-time anyway so this would work out well for me too. My co-workers have also been in touch which has been nice as it keeps me in the loop of what is going on.*

Participant 7, time 3.

In sum, employer support revolved around work adjustments. Work adjustments were introduced as a response to the employee’s high return to work self-efficacy beliefs and perceived work ability for some. This was particularly apparent for one participant who was confident in her ability to return to work whilst undergoing chemotherapy treatment. Similarly, for those on sick leave some employers began to suggest work adjustments including a temporary amendment to a job role and flexible working towards the latter time points of the study (i.e. when participants were in a better position to plan a potential return). Differences between employers / organisations were apparent though. For instance, the two participants that returned to work were both teachers whose employer appeared to draw upon and follow organisation policy as early as time 1. In contrast, others who wished to return but were concerned about their work ability did not seem to be aware that their employer was required to offer reasonable adjustments, such as a female participant who was concerned about managing her stoma whilst at work. A finding that indicates that some employers may lack the necessary knowledge regarding the management and support that should be provided to employees affected by cancer.

*Health Professionals’ Advice and Support*

The support provided by health professionals predominantly related to cancer-specific information as opposed to work-related support, such as following a particular diet, taking time to rest and recover (at baseline) and regarding
treatment. Such advice seemed to help some participants to understand the nature of their disease and therefore enhanced their self-efficacy which enabled them to feel confident about managing their cancer:

Once I have been informed / learnt what is required of me, I have been confident and able to manage my illness and symptoms...Followed guidance and advice given by medical team.
Participant 8, baseline.

Alternatively, when considering the role of support in relation to work matters baseline results show only one participant had received work-related guidance from their health professional; this participant, a teacher, described that she had been warned of the risk of infection associated with her impending chemotherapy treatment. Consequently, she stated that she would take the advice of her consultant prior to returning to work regardless of her own perceived work ability. Subsequent support received from her oncologist coupled with her own perceived self-efficacy beliefs in her work ability enabled her to resume work at time 2. Moreover, diaries indicate that there had been a temporal change in the nature of this participant’s relationship with the oncologist, in that, compared with baseline she was in control of her work decisions. Therefore, results suggest that this participant’s high levels of self-efficacy in relation to return to work coupled with her minimal chemotherapy effects may have enabled this change to occur:

I asked Dr (oncologist name) if I could return to school sometime in late November while still on chemo to deal with exam classes. He said he was ok with this and would be guided by me.
Participant 3, time 1.

Results after baseline showed that another two participants received / sought work-related advice. At time 4, a part-time retail assistant undergoing chemotherapy was contemplating a return to work; however, she stated that she would not return unless it was approved by her oncologist. Alternatively, a 44-year-old bank clerk who had received surgery alone disclosed that her general practitioner had ‘signed her off’ for a period of eight weeks. As a result,
this may have led to this participant assuming that an earlier return would not be possible. Therefore, even though the majority of participants exhibited high self-efficacy beliefs in relation to return to work intentions, a few placed greater importance on the guidance received from health professionals associated with their care. Consequently, this advice/opinion appeared to override their own self-beliefs in their ability to return to work. It was apparent that these individuals did not wish to jeopardise their cancer management or recovery. For instance, one woman was waiting for an appointment which would provide her with the opportunity to discuss her options, whereas a 58-year-old teacher stated that although she felt well and eager to return to work she would not do so until her consultants said she could, particularly as her immune system may be weakened as a result of chemotherapy:

_When my sick note expires / well being is better (return to work intent). Have been signed off for 8 weeks._
Participant 5, time 1.

_Not known as yet (when able to return to work) – awaiting outpatients appointment to discuss options and follow up treatment._
Participant 2, baseline.

_The cancer specialist, thinks that I should be wary about returning before 1/2/09 (last date of chemo) due to the risk of infection. I am hoping that, if all goes well, I might be able to go back to my exam classes before that and return fully after my last chemo – I will take doctor’s advice on this, though as I do not want to do anything to stop my complete recovery._
Participant 3, baseline.

These results suggest that understanding participants’ relationships with their health professionals is essential. This relationship may have influenced participants’ perceived self-efficacy, work ability and return to work intentions. Moreover, for some participants such support may have led to a degree of over-reliance upon health professionals. This is further supported by the findings that for a few participants, high return to work self-efficacy beliefs were overridden by health professionals’ opinions. In other words, these participants
may have been waiting to receive the go ahead to return to work from their health professionals:

*I do have every intention to go back to work. However at the moment the oncologist has advised me not to at least until later on into my treatment.*
Participant 7, time 1.

*I’m feeling much better and quite eager to go back. I need to get the ok from my oncologist first though as recovery comes first.*
Participant 7, time 4.

Overall, when attempting to understand the role of support in relation to self-efficacy beliefs, results suggest that the amount and sources of support may be important. For example, four participants, including two teachers, a retail assistant and a nurse all received positive levels of support from family and friends, employers (including co-workers), and health professionals as a result appeared to exhibit the most favourable self-efficacy beliefs in relation to the management of their cancer and work outcomes. Therefore, for these participants the presence of support from a wide network of individuals may have led to better perceived self-efficacy beliefs:

*Diet has been fine – we eat healthy anyway and my wife has been superb. All in all very confident about ‘managing’ and feeling very positive about my current situation...Seeing friends/family in an ‘organised’ manner i.e. limiting visits has kept up my spirits. I visited work to see colleagues and pupils – this was an uplifting experience. Not becoming bored, by filling time usefully has helped.*
Participant 1, time 2.

6.4. Discussion

The purpose of this study was to explore whether self-efficacy beliefs impacted self-management of cancer and return to work intentions over time. More importantly, the six month study period enabled temporal fluctuations and factors such as support, treatment and work ability that impacted upon these beliefs to be identified. As far as the researcher is aware the role of self-efficacy has not previously been considered in existing cancer and work-related
The results from this study indicate that it is a factor that warrants consideration when investigating work outcomes of those affected by cancer. When attempting to understand how these colorectal cancer patients were managing their cancer and return to work the results indicate that the role of perceived self-efficacy beliefs was diverse. Therefore, the role of self-efficacy and factors impacting upon these beliefs (e.g. support) is somewhat complex. Consequently, based upon the study results, this section aims to map the impact of cancer self-management self-efficacy upon self-efficacy in relation to work including return to work intentions.

The Relationship between Cancer and Work Self-Efficacy

Results suggest that self-efficacy beliefs were important in understanding work outcomes and return to work intentions. Indeed, like cancer management the role of such beliefs was multi-faceted and influenced by various factors. At the start of the study four participants were working. However, at time 1 all but one of the participants was on sick leave to recover from surgery and / or manage chemotherapy treatment. Such findings are consistent with both qualitative (Morrell & Pryce, 2005; Kennedy et al., 2007) and quantitative research (Bradley et al., 2005; Bradley et al., 2006; Pryce et al., 2007; Amir et al., 2007; Short et al., 2005). Of the seven participants that completed two diaries or more, one worked throughout the entire study duration and two had successfully returned to work upon completion of their third diary. This is in line with Bradley and colleagues’ (2006) suggestion that cancer patients take at least one month off from work following diagnosis and treatment. However, this was not the case for the remainder of the study sample. In evaluation, this may be due to different cancer types being utilised in their study. Furthermore, even though the majority of participants were treated with both surgery and chemotherapy, which is not dissimilar to other cancer types, treatment effects and altered bowel habits / symptoms are likely to differ.

For those that were working at some point during the study (n = 6), mean work self-efficacy scores decreased slightly between time 1 (9.00) and time 2 (8.66), although still indicative of high levels, this may have been due to the commencement of chemotherapy treatment. In spite of this, mean work self-
efficacy values increased and stabilised between times 2, 3, 4 and 5 (8.66 vs. 9.00 vs. 9.50 vs. 10.00). Therefore, although these colorectal cancer patients may encounter initial problems at work, perhaps some more so than others, with time research suggests cancer patients’ performance is comparable if not better than those without a history of the disease as suggested by Bradley and Bednarek (2002).

Return to Work Intentions and Barriers

Intentions to return to work were expressed by all that were not working at some point during the study regardless of age and gender. Participants expressed a desire to return to work as it served as a marker of normality that gave them a sense of purpose. This notion of being able to work in order to resume normality is well documented in the literature (e.g. Kennedy et al., 2007). However, results infer that several factors seemed to impact return to work intentions and self-efficacy. Treatment (chemotherapy, fatigue and other symptoms) and decrements in perceived work ability were identified as the most prominent factors. Fatigue was the most commonly reported symptom, which is corroborated by previous research (Spelten et al., 2003). Self-efficacy beliefs in relation to managing such symptoms differed between participants. Some participants were confident in their ability to manage these symptoms successfully whilst maintaining work compared with others. Alternatively, such differences may have arisen because fatigue was perceived differently or, that some participants experienced more pronounced levels than others (Lawrence et al., 2004). The former suggestion may perhaps be supported by lower self-efficacy levels seen in those who perceived fatigue as most troublesome.

Similarly, increased symptom burden such as sore fingers, diarrhoea and nausea coupled with fatigue resulted in poorer self-efficacy in ability to resume work. Additionally, those reporting more symptoms appeared to have a more negative psychological outlook. Hence, these participants exhibited the most temporal fluctuations in both cancer and work-related self-efficacy beliefs. Therefore, in support of research suggesting that a more profound detriment is seen in those reporting more symptoms (Short et al., 2005; Bouknight et al., 2006; Taskila et al., 2007). Moreover, these findings indicate that some of
these factors appeared to serve as barriers to return to work. Figure 6.4 illustrates a model based upon some of the study findings. The premise is that at the most basic level self-efficacy beliefs may have impacted return to work intentions. Therefore, as self-efficacy increased, return to work intentions also appeared to improve. However, the impact of self-efficacy is unlikely to be so simplistic. Instead, high levels of self-efficacy and return to work intentions may have been overridden by barriers such as treatment and self-management skills that appeared to be associated with how symptoms impacted the individual. For some, chemotherapy treatment appeared to lead to symptoms such as fatigue which were difficult to self-manage. Hence, these were return to work barriers even though the intention to return and high self-efficacy beliefs were expressed.

Similarly, the impact of symptoms influenced perceived work ability. The more negative symptom impact the worse perceived work ability was. Therefore, even those who wished to return to work felt unable to fulfil the role.

**Figure 6.4: Return to work barriers.**
Alternatively, for others, low perceived self-efficacy beliefs themselves served as a barrier. For example, those with unpredictable symptoms were less confident in their ability to self-manage, thus return to work.

**Return to Work Intentions and Work Ability**

More importantly a degree of disparity between return to work intent and perceived work ability was evident early on. The level of disparity was further exacerbated in those undergoing chemotherapy treatment some point after baseline. Even though participants wished to return to work and some even managed to work, it was widely acknowledged that perceived work ability was dissimilar to pre-cancer levels. Furthermore, treatment, particularly receiving more than one treatment modality, led to a greater decline in perceived work ability and less likelihood of resuming work. Such decrements in perceived work ability (Short et al., 2005; Gudbergsson et al., 2006; Kennedy et al., 2007) and the impact of treatment upon this have been well documented in prior research (de Boer et al., 2008; Amir et al., 2007). However, some of these studies followed patients who were at least one year post diagnosis (ranged between 1 – 10 years) (Gudbergsson et al., 2006; Kennedy et al., 2007). Therefore, the current study is useful in that it offers an insight into how perceptions of work ability may be impacted soon after diagnosis and during treatment (i.e. early stages). However, it is acknowledged that it would be beneficial to further follow-up these results (qualitatively) to consider how perceived work ability compares with existing quantitative research findings.

In addition, it is worthwhile to discuss the findings reported by de Boer et al. (2008), who followed patients from 6 months after their first day of sick leave, 12 months and 18 months after their first day of sick leave. This is perhaps the most relevant in terms of the current study’s time frame. Unlike de Boer et al. (2008) who reported an improvement in work ability over time, this study’s results suggest that negative impacts upon work ability were apparent once chemotherapy had commenced (i.e. first and second sessions) and appeared to improve only after participants had adjusted to their treatment. The richness of the data enables one to further argue that soon after chemotherapy commenced, self-efficacy beliefs were also negatively impacted due to
symptoms that had surfaced. In spite of this, return to work intentions remained positive on the whole. Within the context of de Boer et al. (2008) this finding is incredibly useful. In other words, existing research indicates that work ability is likely to improve over time. Coupled with this, by exploring work ability and perceived self-efficacy soon after diagnosis this research suggests that the likelihood of decrements in both could occur soon after chemotherapy has commenced. Therefore, this may be the most worthwhile time point to offer some form of intervention, particularly for those undergoing chemotherapy. This is further supported by the finding that perceived work ability appeared to improve soon after participants receiving chemotherapy learned how to self-manage treatment effects. Hence, over time self-efficacy beliefs improved leading to a lessened degree of disparity between return to work intentions and perceived work ability. Additional factors may have also played a role such as the participant’s personality. For example, those who managed to work during treatment may have always possessed a positive work ethic. Thus, even if this disparity between perceived work ability and work intentions was apparent it may have been to a lesser degree. Alternatively, the type of job may have been important. For instance, it is quite likely that an individual with a manual job requiring physical effort will have lower levels of work ability when compared with an individual in an office based role. However, both may still have high return to work intent, but the former would find it difficult to resume their manual role. Consequently, it is important to unpick this further.

Social Support and Self-Efficacy

Support from employers was deemed important to most participants at baseline and the presence of support appeared to enhance self-efficacy. The majority of participants received support throughout the six month study period. As with previous findings, it was found that both emotional and practical support was received from employers and colleagues (Kennedy et al., 2007) and it appeared to be beneficial (Sapp et al., 2003; Michael et al., 2002; Jackson et al., 2007). Participants felt this support kept them in touch with the ‘real world’, thus subsequent return to work intentions appeared to be positively reinforced. As treatment progressed the support was of a more practical nature. Employers
made work adjustments for employees such as working fewer hours or facilitated a phased return to work, something that has previously been reported (Maunsell et al., 1999). In contrast, regarding the role of health professionals the findings are insightful. Less than a third of participants received work-related advice / guidance. Most received support regarding their cancer and treatment management alone. Alternatively, very little or no support was received in relation to work matters. Previous studies also report that cancer patients rarely discussed work issues with their health professionals (Maunsell et al., 1999; Main et al., 2005; Kennedy et al., 2007). Moreover, those who did receive such advice sought it themselves. It may be the case that some health professionals such as oncologists believe cancer patients undergoing chemotherapy treatment will be unable to continue to work during treatment. Therefore, patients may also assume that they are unable to work. Alternatively, it has been suggested that experiences differ from patient to patient; therefore, it would be difficult to offer such advice (Mock, 1998). This is a matter that will be investigated further in the following chapter. Based upon the overall findings regarding self-efficacy in relation to the cancer itself and work Figure 6.5 shows the most favourable outcome as indicated by the results obtained in this study. In short, those who possessed the highest self-efficacy levels in relation to their cancer and work experienced fewest symptoms, hence a more promising psychological outlook compared with those with lower self-efficacy levels. Self-efficacy beliefs were further enhanced by having a wide social support network comprising of family and friend, employers and health professionals. Therefore, the more support an individual had the greater the impact on self-efficacy beliefs. As a result, this led to the increased likelihood of returning to work as indicated by return to work intent and better perceived work ability over the study period. However, in comparison those with less support, in particular, fewer sources of support (e.g. only family and not health professionals and / or employer) may have encountered problems with self-management, thus, more negative self-efficacy beliefs and less favourable return to work intentions.
Support from various sources
- Family and friends
- Employer
- Health professionals

High cancer self-management self-efficacy

High return to work self-efficacy

Return to work
- Higher return to work intentions
- Better perceived work ability

Treatment type(s)
- Fewer symptoms
- Positive psychological well-being

Figure 6.5: Summary of relationship between cancer self-efficacy and work self-efficacy and factors impacting upon these.

Self-Efficacy and Quality of Life

The findings contribute to existing quality of life research, in particular to studies comprising of those affected by colorectal cancer (Karadjova, Shiskov & Petrov, 2007; Tsunoda et al., 2007). For example, Tsunoda et al. (2007) assessed quality of life each month after surgery for a year. Quality of life outcomes decreased in five domains in the month after surgery when compared with pre-operative scores. However, scores improved within three months. In line, with the current study these researchers also reported a difference according to treatment type, whereby less favourable quality of life outcomes were seen in those receiving chemotherapy treatments compared with a non chemotherapy group. Furthermore, the findings from this diary study make it feasible to suggest the possible role of self-efficacy within this area. Self-efficacy may have a direct impact upon quality of life outcomes, however, it may also impact how symptoms and treatment are perceived which in turn could impact quality of life / psychosocial adjustment / work outcomes. Kreitler, Peleg and Ehrenfeld (2007) support this further as they reported a direct impact of self-efficacy upon
quality of life and an indirect impact (i.e. self-efficacy impacted perceived stress, thus quality of life).

**Limitations**

There are some limitations of the diary study. In the first instance, a degree of response bias may have been inherent. Those possessing positive self-efficacy beliefs may have opted into the study due to these beliefs. However, if this was the case it could be argued that participants would have shared similar experiences. Additionally, the results highlight that experiences cannot be understood based solely upon self-efficacy beliefs. Instead, the findings have identified the complex nature of how self-efficacy beliefs, thus return to work intentions / employment outcomes may be impacted by factors such as symptoms, treatment, level of support and perceived work ability. Moreover, the findings suggest that for some even when high self-efficacy and return to work intentions are present, barriers to work (e.g. fatigue and chemotherapy) can take precedence over these beliefs. It was unfortunate that some participants failed to complete more than one diary ($n = 2$). However, the overall response rate (72%) was still promising and the richness of the data was insightful.

**6.5. Summary**

Overall, findings from this study suggest that the role of self-efficacy in understanding the management of colorectal cancer, work ability and return to work intentions is important. Furthermore, as indicated by the results, the nature of this impact is likely to involve additional factors. Therefore, supporting the notion that self-efficacy is unlikely to operate alone as a mechanism governing human behaviour (Bandura, 1997). In the first instance, it seemed that the more treatment effects experienced led to reduced self-efficacy and prevented most from returning to work because of diminished work ability during. However, this was not applicable to the entire sample as some possessed high self-efficacy beliefs to manage treatment (including its effects) and resume work. Instead, external factors such as health professionals may also be crucial, particularly, in relation to understanding how participants
perceived their work ability. For instance, some participants may have been under the impression that they were unable to work during treatment due to a lack of work-related advice / guidance received from their associated health professionals. This is further supported by the disparity between return to work intent and work ability. The majority of participants expressed a desire to return to work; however, decrements in perceived work ability seemed to prevent a return. At this point, it may have been useful to introduce temporary work adjustments for those wishing to work. However, a lack of knowledge on the part of the participants to request reasonable adjustments that they were entitled to from employers may have been apparent.
Chapter 7

7. Exploring the Role of Health Professionals: An Interview Study

7.1. Introduction

When attempting to understand cancer patients’ perceived work ability and return to work intentions it is important to consider the role of health professionals associated with their care. These health professionals are likely to include consultant surgeons, specialist nurses, oncologists and general practitioners. In addition, working-aged patients may also be referred to an appropriate occupational health professional associated with their employer; however, this facility is not always available. Chapters 4, 5 and 6 sought to provide an understanding of the work ability, return to work intentions and employment outcomes of a sample of colorectal cancer patients in the UK. Chapter 4 identified that variations in psychosocial well-being and work ability were apparent, these could lead to changes in return to work intentions; furthermore, differences in these outcomes were detected according to treatment type. Meanwhile, Chapter 5 identified the role of patients’ self-efficacy beliefs in relation to their perceived work ability and employment outcomes. The results from the diary study presented in Chapter 6 identified the more complex nature of self-efficacy, whereby fluctuations in levels of self-efficacy indicate that it is unlikely to be a stable construct. Moreover, a key finding of the diary study was the variation in work-related advice and guidance provided to colorectal patients. Therefore, this chapter aims to explore the role of health professionals, with a view that this, together with findings of Chapters 4 to 6 may help to better inform future interventions to support cancer patients.

There is a limited amount of prior research that has considered the level of information provided by health professionals to patients. However, research suggests this is an area that is in need of improvement. For instance, a recent study with occupational health physicians found that these individuals felt there
was a lack of knowledge and information regarding work and cancer (Amir, Wynn, Whitaker & Luker, 2009). Studies with patients and survivors themselves also suggest that few received work-related guidance from health professionals such as their doctor (Verbeek, et al., 2003; Maunsell et al., 1999; Main et al., 2005; Kennedy et al., 2007). Therefore, this is an area that warrants further investigation as this information (or lack of) may have far-reaching implications for patients, for example, their return to work intentions / outcomes. More importantly, understanding the current practices of health professionals may help towards understanding patients’ perceptions about their perceived work ability. Furthermore, exploring this may help to identify ways in which information (e.g. nature and level of guidance) could be improved in the future. These improvements could not only help working-aged cancer patients but also health professionals who may currently lack the appropriate knowledge to provide such advice / guidance in a confident manner (Aitken & Cornes, 1990).

As a result, health professionals from a number of fields (consultant surgeons, specialist nurses, oncologists, general practitioners and occupational health) participated in a semi-structured interview. The overall objective of the interview study was to explore the nature and extent to which health professionals provide work-related guidance to colorectal cancer. In particular, the aims were:

1. To understand the nature and type of information currently provided to working-aged cancer patients and the impact this may have on patients.

2. To identify factors that may influence the type of information given.

7.2. Methods

Semi-structured interviews were conducted to explore the above stated aims. Prior research studies with cancer patients have reported that health professionals did not discuss work issues or that they provided little work-related advice (Maunsell et al., 1999; Kennedy et al., 2007). However, explanations for such findings are unknown at present. Despite this, these
studies demonstrate the flexible and powerful nature of semi-structured interviews that as a method help to identify new areas of research (Britten, 1995). Earlier interview studies involving health professionals have provided an insight into consultants’ views of patients (Britten, 1991). Similarly, gathering data from various viewpoints is a beneficial way to ensure practice is informed by a credible research evidence base (Green & Britten, 1998). Hence, it seems the most appropriate method to adopt here. Furthermore, according to Pope, van Royen and Baker (2002), semi-structured interviews (and qualitative methods) are useful when exploring quality assessment as it enables “unpacking of the complex issues inherent to quality improvement,” (p. 148). Within the context of this thesis, this study may identify issues / barriers related to current practice of health professionals when providing work-related guidance that were previously unknown (Pope et al., 2002). In addition, identifying improvements to current practice could help towards informing the way work-related advice and guidance is provided to working-aged cancer patients.

7.2.1. Participants

A sample of 18 health professionals comprising of consultant surgeons, specialist nurses, oncologists, general practitioners, occupational health physicians and occupational health advisors participated in this study. Recruitment varied according to the health professional’s field. The consultant surgeons, specialist nurses and oncologists were invited to participate from the NHS Trusts where patients were recruited for the questionnaire and diary studies. The general practitioners and occupational health professionals were recruited via wider research networks. The sampling strategy was therefore determined by the purpose of the research (Morse & Field, 1995) as opposed to attaining statistically representative data (Mays & Pope, 1995; Pope et al., 2002), which is common in qualitative research. The interview study aims and objectives were outlined in the health professionals’ participant information sheet (Appendix 9).
Participant Characteristics

Table 7.1 summarises the demographic profiles of the health professionals that participated in the interview study. The mean age of the participants was 45.87 years (SD = 7.95, range 34 – 57 years) and ten were male (55%). The sample comprised of five consultant surgeons (28%), two occupational health physicians (11%), three colorectal specialist nurses (17%), two oncologists (11%), two general practitioners (11%), two occupational health advisors (11%) and two specialist registrars (11%); one in oncology and the other in occupational medicine.

7.2.2. Interview Schedule

The semi-structured interview schedule (Appendix 10) was designed to identify the extent to which health professionals from a number of fields provided work-related advice / guidance to working-aged cancer patients. It was necessary that the interview schedule could easily be applied to health professionals from different fields. The open-ended nature of questions allowed the researcher to diverge and pursue areas of interest as they arose (Mays & Pope, 1995; Britten 1995). Initially, the interview schedule was drafted by the researcher based upon qualitative findings and findings from the quantitative questionnaire and qualitative diary studies. The draft interview schedule was reviewed by the researcher’s supervisors and two individuals from wider research networks (an occupational health physician and director of cancer research unit). Using a semi-structured interview proforma, the interviews sought to identify the following: the extent and nature of work-related guidance provided by each health professional; factors that impact upon this; the usefulness of this information, and whether any improvements could be made in the future. The researcher therefore attempted to adopt strategies to ensure rigorous qualitative research was carried out as outlined in Mays and Pope (1995).
Table 7.1: Demographic profiles of participants (n = 18).

<table>
<thead>
<tr>
<th>Participant*</th>
<th>Age (years)</th>
<th>Gender</th>
<th>Employment</th>
<th>Tenure</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>56</td>
<td>Male</td>
<td>Consultant Surgeon</td>
<td>13 years</td>
</tr>
<tr>
<td>2</td>
<td>43</td>
<td>Male</td>
<td>Consultant Surgeon</td>
<td>7 years</td>
</tr>
<tr>
<td>3</td>
<td>49</td>
<td>Male</td>
<td>Consultant Surgeon</td>
<td>12 years</td>
</tr>
<tr>
<td>4</td>
<td>42</td>
<td>Male</td>
<td>Consultant Surgeon</td>
<td>4 years</td>
</tr>
<tr>
<td>5</td>
<td>57</td>
<td>Male</td>
<td>Consultant Surgeon</td>
<td>20 years</td>
</tr>
<tr>
<td>6</td>
<td>34</td>
<td>Female</td>
<td>Specialist Nurse</td>
<td>3 years</td>
</tr>
<tr>
<td>7</td>
<td>47</td>
<td>Female</td>
<td>Specialist Nurse</td>
<td>6 years</td>
</tr>
<tr>
<td>8</td>
<td>53</td>
<td>Female</td>
<td>Specialist Nurse</td>
<td>9 years</td>
</tr>
<tr>
<td>9</td>
<td>55</td>
<td>Male</td>
<td>Oncologist</td>
<td>-</td>
</tr>
<tr>
<td>10</td>
<td>41</td>
<td>Female</td>
<td>Oncologist</td>
<td>7 years</td>
</tr>
<tr>
<td>11</td>
<td>40</td>
<td>Female</td>
<td>Specialist Registrar (Oncology)</td>
<td>3 years</td>
</tr>
<tr>
<td>12</td>
<td>55</td>
<td>Male</td>
<td>Occupational Health Physician</td>
<td>-</td>
</tr>
<tr>
<td>13</td>
<td>35</td>
<td>Male</td>
<td>Occupational Health Physician</td>
<td>6 years</td>
</tr>
<tr>
<td>14</td>
<td>-</td>
<td>Male</td>
<td>Specialist Registrar (Occupational Medicine)</td>
<td>4 years</td>
</tr>
<tr>
<td>15</td>
<td>40</td>
<td>Male</td>
<td>General Practitioner</td>
<td>11 years</td>
</tr>
<tr>
<td>16</td>
<td>57</td>
<td>Female</td>
<td>General Practitioner</td>
<td>20 years</td>
</tr>
<tr>
<td>17</td>
<td>-</td>
<td>Female</td>
<td>Occupational Health Advisor</td>
<td>11 years</td>
</tr>
<tr>
<td>18</td>
<td>40</td>
<td>Female</td>
<td>Occupational Health Nurse / Advisor</td>
<td>2 years</td>
</tr>
</tbody>
</table>

* Participant number, individual interviews 1 - 18
7.2.3. Procedure

Participants were invited to take part in a face-to-face interview. All interviews were conducted at the participant’s place of work and arranged at a convenient time for them. Participants were provided with a participant information sheet (Appendix 9) that outlined the aims of the research and what the study involved. Prior to completing the informed consent from (Appendix 11), those wishing to participate were given the opportunity to ask questions regarding the interview and / or study. Demographic information including age, gender, occupation and tenure was collected from each participant. After eighteen interviews with at least two health professionals from each field, the researcher felt that data failed to generate anything new and had reached saturation (Mason, 1996). Therefore, no further health professionals were invited to participate. Interviews lasted between 15 and 40 minutes, were digitally recorded and transcribed verbatim.

7.2.4. Analysis

The transcript data generated from the interviews was analysed using thematic analysis (see Chapter 6, pp. 131-132). The analysis process involved the researcher and an independent researcher systematically reviewing the interview transcripts separately. Initial ideas were noted, which guided preliminary codes. These codes were grouped into potential relevant themes and discussed between the researchers. Further analysis clarified the specific nature of each theme leading to the development of names for each theme. Following agreement of the themes identified, extracts were taken from the transcripts to exemplify each theme and reflected the overall accounts reported by participants. During the analysis process it was also noted that differences and similarities regarding work-related advice and guidance were apparent according to the health professional’s field. Therefore, results will also be presented taking this into account.

7.3. Results

Four core themes were identified, which are summarised in Table 7.2. These will be discussed in turn.
The Nature of Current Practice

Participants described the type and level of work-related guidance they had previously given to patients that were in employment at diagnosis. The level of patient contact varied according to the health professionals’ field and differences within groups were also evident. For example, up to four patients diagnosed with cancer were referred to the occupational health professionals each month. One general practitioner stated that he saw between two and three cancer patients each week; whilst a female general practitioner saw just as many in a month. The amount of time spent discussing work matters varied. As expected the consultant surgeons, consultant oncologists and specialist nurses had the most frequent patient contact. Therefore, these individuals were likely to have the greatest opportunity to address work matters. For instance, one consultant surgeon mentioned that he met with each patient up to 20 times. The specialist nurses pointed out that patients were given a contact number and were able to call the centre whenever they wished. Subsequently, the matter of how to manage work usually arose at some point during the cancer pathway with at least one or all health professionals. However, the initiation and timing of the discussion varied.

Initiating the Discussion about Work

Participants discussed work with employed patients at different time points. According to the specialist nurses, for patients receiving surgery, the first outpatient appointment proceeding discharge was a good opportunity to discuss the management of work. This was argued to be an appropriate time to address the matter because by this time consultants (surgeons and oncologists) knew whether further treatment would be required. Therefore, patients have been given information post surgery but prior to any other
Table 7.2: Themes and sub-themes.

<table>
<thead>
<tr>
<th>Key Themes</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Nature of Current Practice</td>
<td>Initiating the Discussion about Work</td>
</tr>
<tr>
<td></td>
<td>How Information is Delivered</td>
</tr>
<tr>
<td>Factors Impacting the Provision of Work-Related Guidance</td>
<td>Diagnosis and Prognosis</td>
</tr>
<tr>
<td></td>
<td>Treatment and Symptoms</td>
</tr>
<tr>
<td></td>
<td>Nature of Employment</td>
</tr>
<tr>
<td>Barriers to Providing Work-Related Support</td>
<td>Lack of Knowledge</td>
</tr>
<tr>
<td></td>
<td>Insufficient Evidence Base</td>
</tr>
<tr>
<td></td>
<td>Patients’ Perceptions and Attitudes</td>
</tr>
<tr>
<td></td>
<td>Time Constraints</td>
</tr>
<tr>
<td>The Need for a Multifaceted Approach</td>
<td>A Two-Stage Approach</td>
</tr>
<tr>
<td></td>
<td>Role of the Patient and Employer</td>
</tr>
</tbody>
</table>
treatment (e.g. chemotherapy). In spite of this, a few participants, in particular the consultant surgeons and oncologists stumbled upon this topic more than once. For example, one consultant oncologist stated that he brought up the topic on several occasions:

*Patients often want to know about work quite early so probably once they’ve come to terms with their diagnosis, a week or two after they’ve been told and before starting their treatments.*
Participant 9, Consultant Oncologist.

Alternatively, the occupational health participants met with patients after they had been referred by their employer or manager. This was most likely to be when the patient was considering a return to work:

*It’s the point at which somebody refers, and sometimes I’ll be referred at an early stage, and sometimes I’ll be referred when somebody’s about to come back to work; that’s probably more common.*
Participant 17, Occupational Health Advisor.

However, four participants, all consultant surgeons, stated that they rarely had a discussion about work with their patients:

*It’s not part of normal practice. Patient asks time to resumption to normal activity, I don’t remember specifically talking to a patient about resuming work. It doesn’t really cross our minds.*
Participant 4, Consultant Surgeon.

Further to this, an occupational health physician (participant 14) mentioned that he asked his patients if they had spoken about work with their specialist, they often said that they had not. Subsequently, the majority of the consultants pointed out that patients often initiated the conversation themselves soon after diagnosis. Therefore, this suggests that this may have been an important matter on the patient’s mind at an early stage. Participants revealed that patients approached them with common questions such as whether or not they should work during treatment, length of time to take off work (e.g. after chemotherapy or surgery) and the risk of infection associated with
chemotherapy. A consultant oncologist also said that some patients were relaying questions asked by their employer:

_They will often bring to me questions that the employer has already asked, practicalities if their job involves fairly heavy lifting, or strenuous work._

Participant 10, Consultant Oncologist.

**How Information is Delivered**

All participants said that work-related guidance was informally given to patients in a verbal manner. A consultant surgeon attributed this to the fact that advice often needed to be tailored to suit each patient individually. Written guidance was minimal and provided advice on tasks involving heavy lifting and driving, however, this was not specific to work. All but one participant (occupational health advisor) felt that some form of written work-related guidance would be helpful to give to patients:

_At the moment we don’t have any written information to give patients, so may be if there is that information for each specific cancer we should be able to help; there might be some available at the moment, but I must say that I’m not giving any away._

Participant 16, General Practitioner.

_I give verbal advice…I think people like access to written literature…can be really helpful because it’s all there in logical form._

Participant 17, Occupational Health Advisor.

**Factors Impacting the Provision of Work-Related Guidance**

When providing work-related guidance it was clear that health professionals took into account a number of factors including the nature of patients’ diagnoses and prognoses, treatments and symptoms and the type of work they were engaged in at diagnosis. This appeared to be irrespective of the health professional’s field.
Diagnosis and Prognosis

The importance and purpose of diagnosis and prognosis information in the provision of work-related guidance differed between participants. For health professionals, such as the consultant surgeons, oncologists and specialist nurses, the primary purpose of diagnosis information was to help decide upon the treatment to be administered to ensure the best possible prognosis for the patient. The implications of prognosis upon work ability appeared to be a secondary matter. A female specialist registrar (oncology) seemed to presume that a poor prognosis was likely to lead to the patient withdrawing from employment almost immediately; hence, the amount of work-related advice that would be offered for such a case was likely to be limited:

Sometimes we see poor prognostic cancer...so in the short term it may affect everything, so they may decide to go off work at an early stage and so we involve the Macmillan team rather than us going through it.
Participant 11, Specialist Registrar (Oncology).

Alternatively, a male specialist registrar training in occupational health described how this information from oncology helped to understand the potential impact of the cancer on a patient’s work ability. Furthermore, this information helped to guide the management of an employee with cancer. However, it was apparent that efforts to obtain this information were necessary and for this reason it may not have been accessed on every occasion:

What I normally do is I obviously try and establish the facts of their illness. We’re a little limited in that because as Occupational Health we’re not part of the medical loop, we’re agents of the employer. So we don’t have their medical records to look at...I do often write to the specialist...so at some point we will have the specialist’s report, which will give us a diagnosis and possibly an indication of prognosis...the focus of my role would be to look at functional capabilities and to see how the cancer is affecting them both in their home life and also at work...we make it clear that, yes they are probably going to have ongoing problems and that’s probably as far as I would go in terms of a negative prognosis.
Participant 14, Specialist Registrar (Occupational Health).
When discussing an employee’s ability to work with the individual’s employer or manager, one occupational health physician stated that the diagnosis itself was a barrier that had to be overcome. This participant described how managers quite often did not understand that cancer is increasingly being viewed as a treatable illness. Consequently, this indicates that employers may also require more tailored information about cancer and how to manage an employee with cancer.

Treatment and Symptoms

The entire sample specified that the nature of a patient’s treatment was an important factor taken into account when discussing matters related to work. For those undergoing surgery, three consultant surgeons and the three colorectal nurse specialists stated that patients were advised that a period of at least six weeks leave from work was necessary to aid recovery. However, participants’ perceptions regarding the amount of time deemed necessary for recovery after a surgical procedure for colorectal cancer varied. Furthermore, differences between participants within the same field were evident. Hence, this suggests that patients may receive different guidance according to the individual responsible for their care:

*About six to eight weeks, not to lift anything heavy, so if they’re manual labourers, for example, we try and tell them not to lift anything heavy for about eight weeks.*
Participant 2, Consultant Surgeon.

*I’m taking it from after surgery, so that’ll be the usual post-operative recovery that we tell them, which is that basically the recovery time is six weeks...generally we say take the first six weeks and see how you are, to recover from the surgery.*
Participant 8, Specialist Nurse.

*We discuss discharge information with them, and we are telling them not to go back to work until three months after surgery, especially if they have had a bowel resection.*
Participant 7, Specialist Nurse.
As well as surgery, a number of colorectal patients are likely to undergo chemotherapy treatment. This was another factor that was taken into account by participants when discussing work matters with patients. An occupational health physician discussed that chemotherapy posed challenges when attempting to keep people at work. It was apparent that the level of advice provided to working-aged patients during treatment varied between participants. This was because certain health professionals (e.g. oncologists) had more contact with patients than others during this time. For instance, the two general practitioners stated that they frequently met with patients during the early stages of their cancer journey where the discussion regarding work was inevitable as it was their role to issue sick notes. It was during these consultations that work ability was discussed. The general practitioners also attempted to gauge the opinions of other health professionals via the patient (but not directly from specialists themselves), which helped to decide the length of time subsequent sick notes would be issued for:

> When we give them a sick note, so if you were the person we'd be saying how are you doing, all the rest of it; has the hospital given you any idea of how long this is going to take, how you might feel. Then I can issue a certificate, depending on what I think is a reasonable amount of time.
> Participant 15, General Practitioner.

Once treatment was underway the general practitioners saw patients less frequently. Moreover, due to differences in treatment and cancer type they found it more difficult to provide work-related advice. For a female general practitioner, specialist nurses were seen to be better placed to discuss when a return to work would be possible:

> It's difficult for us to give a time limit...There's usually a cancer nurse attached to the unit where they have the treatment, so they can go back and they review them every so often and check whether they are ready to go back to work.
> Participant 16, General Practitioner.

However, it emerged that specialist nurses had conflicting opinions:
You need to go back to your general practitioner to make sure that you’re fit to work because we don’t see them so often...to be quite honest the information we’re giving is just based on treatment that they’re having at the hospital really.

Participant 7, Specialist Nurse.

Views about ability to work (where work ability is defined as: the ability to perform job with respect to demands, health and mental resources, Ilmarinen et al., 2005) during treatment differed among participants, which in turn impacted the type of work-related advice given to patients. A consultant surgeon stated that they helped patients plan their work around their treatment:

We help them plan their work around their treatment. We tell them how much time they will probably need to off work and give them a realistic view about how soon they will be able to go back.

Participant 2, Consultant Surgeon.

The specialist nurses mentioned that they liaised with the patient’s consultant surgeon and oncologist when patients raised questions about their work ability in relation to their chemotherapy treatment. In particular, oncologists seemed to be in the best position to offer such advice, perhaps due to their knowledge about treatment types and the associated side-effects:

If the patient raises issues about work, say if they are starting chemotherapy, I will discuss that with their consultants. Our oncologist is very good, he will sit down and discuss that bit further with them and discuss how it’s going to impact on their work.

Participant 8, Specialist Nurse.

Alternatively, a female consultant oncologist stated that some patients were told that they would be unable to work during chemotherapy treatment, when in fact there was no real reason why they could not continue to work. Another oncologist mentioned that the type of chemotherapy treatment was important when advising a possible return to work. Additionally, a ‘see how you go’ approach was often advised:
I usually just say if I were you I would take time off during treatment...If it’s very aggressive chemotherapy which might leave them open to infection, I would advise not returning to work. If it’s very gentle, easy chemotherapy I’d say, if you want to go back to work and you find treatment easy then go back to work.

Participant 9, Consultant Oncologist.

It was acknowledged by most that the type and nature of symptoms experienced by patients was variable. Nevertheless, such symptoms were likely to impact work ability and the type of advice given about resuming work. For example, a specialist nurse pointed out that symptoms such as fatigue, constipation or diarrhoea would make it difficult to work during treatment. Furthermore, another nurse felt that decisions about when to return to work were ultimately best left up to the patient:

*It depends on the symptoms really and I think the patient himself is the best judge on whether they are able to work or go off sick.*

Participant 7, Specialist Nurse.

Results suggest that the participants felt that patients who experienced fewest symptoms were in a better position to either continue with work or return to work. Therefore, in such cases, the health professionals were perhaps more likely to offer more specific work-related guidance to these individuals:

*Chemotherapy brings about its own challenges for trying to keep them in work...Occasionally the chemotherapy that people receive tends not to cause any side effects and they are able to stay at work through it, apart from the days that they can’t attend because they are receiving treatment.*

Participant 13, Occupational Health Physician.

**Nature of Employment**

Participants spoke about how understanding the type of work a patient was engaged in prior to diagnosis was important when providing guidance on how to manage work. All participants said that being employed in a manual job was associated with being less likely to continue with work. For example, a consultant surgeon stated that due to diminished physical work ability
were advised to temporarily amend their tasks where possible. Likewise, patients taking part in work requiring physical effort such as lifting and handling were often advised to take more time off work than those in non manual jobs:

*It also depends on the type of work they do. If it is a heavy manual job you don’t expect them to return quickly, you need to continuously assess them, what they can perform, and advise appropriately.*

Participant 16, General Practitioner.

In contrast, one consultant surgeon felt that the type of guidance he provided was limited as he was not always sure about the precise nature of an individual’s work:

*They’ll usually say I work in a factory, I’m an IT consultant...so one can have a conversation and I have my own imaginings about what being an IT consultant means. But I don’t actually know exactly what they do every day or what their job demands are.*

Participant 5, Consultant Surgeon.

Differences in the extent to which work matters were discussed with patients were also dependent upon whether the individual was self-employed. The consultant surgeons, specialist nurses and oncologists all pointed out that patients who were self-employed were more eager to return to work when compared with those that were not self-employed. As a result, work matters were discussed quite early and seemed to be more extensive with self-employed patients, usually because the patient had raised the topic themselves:

*The self-employed people will probably be wanting to get back before those that have got sick pay and things. They tend to recover quicker because they haven’t got any choice really.*

Participant 6, Specialist Nurse.

*Self-employed people have a completely different approach from somebody who has employment benefits.*

Participant 2, Consultant Surgeon.
Type of work was also likely to impact whether the individual would be able to work during treatment, manage a colostomy and the type of adjustments that could be offered by the employer:

*If someone is going to be off one week in four for chemotherapy...the manager has to be able to allow their absence. If they’re packing something in a factory or on a production line some managers will say, I can’t tolerate that.*

Participant 14, Specialist Registrar (Occupational Medicine).

*In warehousing there is an awful lot of bending and lifting, manual handling, so depending where the colostomy is sited and how well their colostomy fares, it might not be a suitable environment...in warehousing there aren’t any light duties, the only adjustment you can make are hours.*

Participant 18, Occupational Health Advisor.

**Barriers to Providing Work-Related Support**

When attempting to provide work-related guidance to patients, participants spoke of a number of barriers that prevented them from being able to give as clear advice as they perhaps wished. A lack of knowledge and an insufficient evidence base were commonly referred to as barriers. Further to this, patients’ perceptions and their attitudes also served as barriers when trying to discuss work matters.

*Lack of Knowledge*

The majority of the health professionals felt that their knowledge about the impact of cancer on work ability and employment outcomes was rather limited. Consequently, this made it challenging when advising patients about work decisions. All of the consultant oncologists and specialist nurses stated that their lack of knowledge about employment law and matters related to finances after a cancer diagnosis made it difficult to answer patients’ questions. One consultant surgeon felt that knowing more about patients’ social circumstances, nature of their occupation and their relationship with their employer would make a favourable difference when offering guidance. Therefore, most participants
revealed that the guidance they have provided to date was largely based on their prior experiences with patients that were employed at diagnosis:

*We haven’t got that much information to give patients, we’re just going from what we’ve advised other patients in the past.*
Participant 8, Specialist Nurse.

*I tend to give as much information as I can, within my limitations. I will not be commenting about something I don’t know a lot about.*
Participant 15, General Practitioner.

Regardless of their field, participants appeared most confident when guiding patients about tasks they should avoid; namely heavy lifting and physically demanding work. However, providing such clear advice was not always possible when considering treatment such as chemotherapy. This was due to differences in treatment effects and outcomes:

*We’re a little bit uncertain as to what the treatment will be or what the outcome will be; so we’re sometimes a bit hesitant about that...with some people the operation doesn’t go well, or the chemotherapy doesn’t go well.*
Participant 12, Occupational Health Physician.

For the occupational health professionals, this lack of knowledge was problematic when liaising with the patient’s employer. In particular, employers often wanted precise details of what an employee diagnosed with cancer could do and when they would be likely to return to work. However, one occupational health physician stated that not knowing all the facts about the individual’s cancer and treatment made it difficult to answer such questions. In contrast, an occupational health advisor argued that it was important to understand matters from the viewpoint of the employer:
I probably ask a lot of employers, and I think health services do...we’re saying it’s going to be months before somebody is back up to full speed...it’s an awfully difficult thing for an employer to manage, and I don’t think we take account of that...an employee tends to feel that they’re entitled to have their job back...and I think that’s not always realistic.

Participant 18, Occupational Health Advisor.

**Insufficient Evidence Base**

Health professionals’ lack of knowledge as a barrier to providing guidance could be attributed to a limited evidence base. Most participants felt that there was an unsuitable evidence base within their profession to draw upon when giving advice or discussing matters related to work. A consultant surgeon disclosed that although little evidence was available about when cancer patients should get back to work, there was very wide practice. He went on to suggest that such varied practice was often likely to lead to different patient outcomes as a result of the individual involved in their care. Consequently, this was likely to result in conflicting opinions and may even impact relationships between health professionals from different fields:

> Even if I said you’ll be back at work in a month, there are other things beyond our control, like occupational health, like their general practitioners who will override that...So whatever we think doesn’t make a difference...I think keeping people off work is very bad for their brains, I really do. I get so irritated when people do, and there’s nothing I can do about it.

Participant 1, Consultant Surgeon.

The availability of resources to refer to about the type and nature of advice to provide was deemed inadequate by most. For example, four participants stated that information about how a stoma appliance may impact work ability was scarce. As a result, these participants may have been unsure about the usefulness and appropriateness of their guidance:
There is not much guidance, either from the Department of Health, as to what should be the advice. There is very little info, especially for cancer patients with a stoma.

Participant 2, Consultant Surgeon.

There’s a fairly weak-ended space for much of the advice we give in my profession unfortunately and that’s something highlighted by Carol Black. The evidence base for the return to work with the diagnosis of cancer is virtually non-existent.

Participant 12, Occupational Health Physician.

I’m not given any real guidance; there are no guidelines to me to say, this is what you should or shouldn’t say. I generally have my spiel after my experience of looking after patients...It might be my complete lack of knowledge...I don’t really have a handle on how many patients do get back to into the workplace successfully.

Participant 10, Consultant Oncologist.

Some participants did however provide examples of resources that they made use of when providing work-related guidance. For instance, a female specialist registrar (oncology) said that she utilised quality of life data related to treatments that was based upon research conducted within her NHS Trust. In an effort to answer patients’ questions a general practitioner and several participants from the field of occupational health described attempts to access information on the internet:

I’m quite good with the internet...I read and update my knowledge, so I know each and every cancer, at least in a superficial way.

Participant 15, General Practitioner.

Moreover, a specialist registrar training in occupational medicine suggested that an insufficient evidence base and lack of knowledge was reflected by patients who appeared to have a number of unanswered questions:
What emerges is that a lot of people seem to feel that they’ve not got adequate information from their hospital appointment, and sometimes their GP, and they’ve still got unanswered questions...the evidence base in much of occupational health is pretty limited to the very basics.

Participant 14, Specialist Registrar (Occupational Medicine).

In contrast, two other occupational health professionals felt there was a suitable and sufficient evidence base for them to draw upon to confidently advise individuals about how to manage their cancer, treatment and work. When dealing with cancer in the workplace, an occupational health advisor felt that existing policies and procedures for managing employees with ill-health were transferable to cancer patients:

*I think it’s not necessarily identifying cancer. If you have a policy and a procedure that works for everybody, for all conditions, then you will meet the needs of the people who’ve got a diagnosis of cancer...The only slight difference might be the psychological issues.*

Participant 18, Occupational Health Advisor.

Patients’ Perceptions and Attitudes

Seven participants, with at least one from each field, expressed that patients themselves were sometimes a barrier when discussing how to manage work. Unsurprisingly, participants stated that work was the last thing some patients wished to discuss. On the other hand, one specialist nurse stated that patients that used denial as a coping strategy did not wish to discuss the cancer let alone their employment. In line with this, an occupational health physician spoke about patients who did not want to know about their prognosis. This led to problems when trying to assess work ability and potential outcomes. A general practitioner and a consultant surgeon thought that various perceptions made it difficult to offer generic advice to patients. Subsequently, some participants highlighted the importance of identifying the needs of the patient prior to providing work-related guidance:
People are so different, some people see having cancer as a challenge that they must overcome and have quite a strong work ethic...Other people shrivel up and think, I can never do anything ever again...you’ve got the cancer to manage, but you’ve also got the person to manage. I think you would need some sort of face-to-face assessment.

Participant 15, General Practitioner.

Patients sometimes feel that they, because they’ve got a diagnosis of cancer they can’t go back to work. A lot of patients feel the diagnosis of cancer is an end of life diagnosis for them and you have to take them back from there and say, actually no, we are aiming to cure you of this problem...should you want to, you can carry on working but there’ll be a period of time when you won’t be able to work.

Participant 3, Consultant Surgeon.

Time Constraints

Apart from the occupational health professionals, the remaining health professionals felt that work matters were not discussed at length or at all because of the limited consultation times that they had with patients. Furthermore, participants felt that patients were already bombarded with a wealth of information about their diagnosis, surgery and treatment that it was difficult to have a discussion about work. This was common early on in the cancer pathway and reflected by the results that some patients initiated a discussion about work themselves. Similarly, a specialist registrar (occupational health physician) disclosed that patients came to him with a number of unanswered questions. In spite of such time constraints participants appeared more than willing to offer work-related guidance:

I certainly would be happy to be taught something about work for patients on chemotherapy and to provide some advice; but probably the clinic that I do which is really busy and very focused on treatment, might not be the best use of our time.

Participant 9, Consultant Oncologist.
The Need for a Multifaceted Approach

Participants provided an insight into the way work-related guidance could be improved in the future. It was acknowledged that a level of consistency was required at a national level. It was rare for participants to identify a sole individual who could be responsible for offering such guidance and advice. Three participants did however suggest that specialist nurses could have a pivotal role:

_We are the link, we’re the key workers for the patients and if they have queries or questions, they’re the first ones to give us a call at the centre._

Participant 8, Specialist Nurse.

In spite of this, participants argued that a multi-disciplinary or holistic approach would be the most effective strategy to adopt. Subsequently, such an approach would involve a number of health professionals. The degree of involvement however would vary. Two general practitioners suggested that it would be appropriate if they initiated the first discussion about work with patients. It could be argued this is inevitable as general practitioners assess fitness for work and issue sick notes. Eleven other participants mentioned that guidance could be offered according to where patients were in the cancer pathway and by the appropriate health professional:

_It’s probably a multidisciplinary approach…I think we need a certain amount of information and advice…We are not all of us, trained as occupational health physicians._

Participant 2, Consultant Surgeon.

_It’s definitely something that surgeons should involve themselves with…but we’re all part of the bigger team…there should be ‘the information’ that’s available, and it should come to the patient from different sources…Compartmentalising information could be dangerous. We all need to know about it and discuss it with patients at any given interaction._

Participant 4, Consultant Surgeon.
Four participants also suggested that it would be useful to have an independent person allocated with this role to which patients be referred. This solution would overcome the time constraints and the health professionals' lack of knowledge:

*It might be much better for the patient and us to have a separate place to go and talk about that sort of thing with somebody much more knowledgeable about it. It doesn't have to be in the hospital; we could always, if it existed, refer them to somebody who knew about that.*

Participant 9, Consultant Oncologist.

*We need somebody to be able to signpost to, because we have more than enough to contend with at the moment, we don't have time; but it's actually true, we won't have time to do that with them...need someone who would be able to actually go through all this talk with them...that would be a good idea.*

Participant 7, Specialist Nurse.

As a result, participants recognised that providing guidance on several occasions would be most worthwhile. Developing a two-stage approach comprising of verbal and written material was presented as an idea by the majority of participants.

**A Two-Stage Approach**

It was suggested by most, more vehemently by the consultant surgeons, oncologists and specialist nurses, that providing guidance in two stages would be useful. Although participants found it difficult to suggest the precise timing of this process the health professionals did share similar ideas. For example, eight participants suggested that generic work-related guidance could firstly be given to patients at an early stage, soon after diagnosis. Following this, it was argued that further guidance could be tailored over time according to the patient's treatment plan, treatment effects, his / her work, prognosis and return to work intentions:
I think because of the variability of the procedures we’re doing with bowel cancer and the variable outcomes, it has to be fairly independent or bespoke advice you give them because everybody’s slightly different. But there’s a standard amount of information you can give people. For example, if they’re within working age, you would expect them to go to work eventually.
Participant 3, Consultant Surgeon.

I think they need guidance right at the beginning so they’ve got realistic expectations as to how long they’re going to be off; then again, when they’re getting towards the end of their episode, to discuss return to work.
Participant 17, Occupational Health Advisor.

I think verbally, but also back up with written support, written information as well...like I said before, they feel they are getting too much...it doesn’t have to be a huge leaflet, just pointers probably, just so that they know what they can and can’t do.
Participant 8, Specialist Nurse.

**Role of the Patient and Employer**

Within this potential multi-faceted approach, three participants also commented on the role of the patient and employer. For example, two consultant surgeons and an oncologist suggested that patients should contact their employer at an early stage to discuss adjustments that could be made to facilitate their return to work:

*Talk to your employer and see what they think about a staged return to work or whether you would expect them to have you back...As a principle, you should be able to get back to work, but just talk to them about it*
Participant 1 Consultant Surgeon.

*Firm believer in a phased return...And again, if they are going to go on chemotherapy, they absolutely must make sure that their employer knows.*
Participant 10, Consultant Oncologist.

Similarly, for an optimal outcome, four participants highlighted that the patient’s employer needed to be involved in the process. For example, a consultant surgeon suggested that with a patient’s permission, health professionals could
discuss the patient’s capabilities with his / her employer. Another participant felt that the psychological impact of cancer often failed to be acknowledged by employers and therefore could lead to problems in their management:

*Both of those two (cancer and coronary artery disease) have a huge psychological effect...The arrangement is that if the NHS cures your cancer they expect you to go back to work. But when you look at an individual case, somebody may be in their 50s...they’re psychologically just not well enough to go back to work. They won’t get that pension often because it’s deemed that they’re physically fit enough to go back.*

Participant 14, Specialist Registrar (Occupational Medicine).

However, this may simply be due to employers’ lack of knowledge about the impact of cancer on work ability. Five participants, from various fields, suggested that developing some form of guidance to educate employers about the impact of cancer, and in particular treatment effects (including stoma advice) could also aid the return to work process:

*There’s a lot of organisations where it’s just the manager, and in some ways if there was a generic leaflet or something like that, that will probably be helpful to them as well, because I don’t know where they go for advice.*

Participant 12, Occupational Health Physician.

These results have identified ways in which work-related guidance could be improved. Furthermore, it seems that the most promising approach is likely to comprise of a multi-disciplinary effort that involves the patient and their respective employer. Such an approach appears as though it would produce more favourable outcomes, such as a quicker return to work and high rates of work resumption.

**7.4. Discussion**

When attempting to understand how individuals affected by cancer manage their employment, little is known about the role that health professionals may have in work outcomes. Therefore, the primary aim of this research study was to investigate the level and type of work-related guidance health professionals
provide to patients. By identifying current practices and the factors impacting upon these, researchers can work towards designing and implementing appropriate interventions to provide work-related guidance to support working-aged patients. Although the health professionals that participated in the study were drawn from different fields, it was likely that they would all meet a cancer patient at some point during their pathway (not including occupational health professional). Furthermore, this approach allowed the researcher to study the provision of work-related support during follow-up care. This is in line with a suggestion presented in prior research, where Verbeek and colleagues (2003) argued that with the continuity of care, more specific guidance (e.g. work-related) could be possible.

The findings indicated that health professionals did attempt to provide work-related guidance to patients where possible. However, in other qualitative studies cancer patients and survivors reported that they received little or no work-related guidance from their treating health professional (Maunsell et al. 1999; Kennedy et al., 2007). Findings from the diary study reported in the previous chapter also identified that only a small number of patients discussed the management of their work with health professionals. In addition, those who did discuss the management of work often initiated the conversation themselves. These results provide an insight into the possible reasons for such findings that to the researcher’s knowledge have not previously been presented in detail. It was apparent that all of the participating health professionals felt that they lacked the necessary knowledge to provide the most appropriate advice; a finding that is supported in a study with occupational physicians (Amir et al., 2009). Moreover, they were unaware of what was deemed to be the most suitable approach. Other results infer that an insufficient evidence base for health professionals to draw upon is also part of the problem. Even consultant surgeons, oncologists and specialist nurses mentioned that the absence of guidelines made it difficult to ascertain the level and type of guidance that should be provided to patients. This is somewhat concerning as these participants appeared to have the most contact with patients. This is further supported by Aitken and Cornes (1990), who argued that consultants and specialist nurses are unaware of what their role in the return to work process
should be. Therefore, unsurprisingly it was common to find that health professionals were being guided by past experiences with patients who were employed at diagnosis.

Encouragingly, when considering the current practices of health professionals a degree of consistency was apparent. This was irrespective of the health professionals' field. When providing work-related support, participants usually took into account the patient's treatment, symptoms, prognosis and type of work. However, time constraints made it hard to take into account wider issues, such as the patient's precise job demands, relationship with their employer or social circumstances. Similarly, time constraints and pressures prevented some health professionals from being able to give patients the full support they wanted to provide. Research already indicates that stress and burnout is a concern in colorectal consultant surgeons (Sharma et al., 2008). Consequently, when considering prior research (Maunsell et al., 1999; Kennedy et al., 2007) and the findings from the diary study, it is unlikely that health professionals were unwilling to discuss matters related to work. Instead, certain barriers may have prevented them from being able to give the guidance they wanted to give.

Arguably, such an inconsistent approach is likely to result in varied practice. It was apparent that the participating health professionals had opposing views on matters such as the length of time needed to recover from surgery and whether patients should work during chemotherapy treatment. More concerning was that differences were evident between participants from the same field. As a result, differences in patients' work outcomes could also be explained by the beliefs and practices of the patients' health professional. Therefore, supporting the notion that the role of health professionals is pivotal in helping patients re-enter the workplace after a cancer diagnosis (Verbeek, 2006). Subsequently, having a consistent approach, perhaps in the form of guidelines may help towards ensuring that the most appropriate guidance is being provided to all patients.

The interviews yielded insightful suggestions about the possible design, structure and implementation of future intervention endeavours. It was
encouraging to find that the majority of participants felt that some form of intervention was required to ensure patients were provided with the most appropriate work-related guidance. The most effective strategy was suggested to be one that involved various health professionals. This would include the general practitioner, consultant surgeons and / or consultant oncologist, specialist nurses and where possible an occupational health professional. Additionally, incorporating the patient and their employer in the process was deemed to be important. Therefore, suggesting that a concerted effort was necessary for the best possible outcome. It also emerged that having a two-stage process would perhaps be the best way forward. Participants commonly stated that this could comprise of generic work-related guidance at the outset (e.g. soon after diagnosis), followed by tailored or bespoke advice based on the patient’s individual needs (e.g. treatment, side effects and type of work). Similarly, a mixture of verbal and written information would help to overcome time constraints and enable patients to refer to the guidance when it suited them (e.g. written guidance when they are thinking about returning to work). However, it could be argued that such a multi-disciplinary approach would require one individual to have a more centred role. Some participants did suggest that an individual needed to be assigned this role to ensure that the best service was offered. Alternatively, some felt that specialist nurses would be in a good position to provide the bulk of the guidance. However, the specialist nurses themselves disclosed that time constraints and a lack of knowledge already prevented them from being able to deal with questions posed by patients.

Although the findings appear to be of immense value, the research is not without its limitations. Firstly, the sample is relatively small. However, in spite of this, the richness of the data generated from the interviews is reflected in the findings. The researcher only managed to recruit two general practitioners. It is acknowledged that it was most difficult to recruit individuals from this group. Furthermore, these participants were interviewed last, and it was felt that nothing new was emerging from the interview data (Mason, 1996). Hence, two general practitioners were deemed to be sufficient. Moreover, this is the first study that has included all of the different health professionals that are likely to
be involved in the care of working-aged cancer patients. Therefore, by considering their current practices, barriers to better practice and the apparent gaps researchers can inform future intervention development.

7.5. **Summary**

The results from this study indicate that health professionals do attempt to provide guidance to working-aged patients. However, the nature of such guidance is likely to vary due to experience, knowledge and time constraints. Nevertheless, the results that emerged indicate that health professionals draw upon certain factors to inform the type of guidance they give patients. For example, the nature of their treatment seemed to be important. Even though participants mentioned that they did their best to guide patients about the management of their work, they highlighted a number of barriers. Indeed, the most common barriers to providing more appropriate guidance was associated with a lack of knowledge held by the health professionals and an insufficient evidence base for these individuals to draw upon.

The findings suggest that there is a gap in the provision of work-related advice and guidance for individuals affected by cancer. Furthermore, the findings presented and discussed here and in Chapter 6, indicate that such guidance is a valuable aspect of patient care that currently falls short. Moreover, it could be argued that it would be unrealistic to expect any one health professional to be responsible for providing this guidance. However, it can be suggested that a two-stage process comprising of generic guidance that is later tailored to meet each patient's needs seems most suitable. Equally, it is possible to argue that both health professionals and employers require some form of guidelines about their role in this arena. Ultimately, this would help towards ensuring that patients and employees are given consistent advice and support, which in turn could help attain better work outcomes.
8. Discussion

This thesis sought to investigate the role of self-efficacy beliefs upon work ability, return to work intentions and employment outcomes in a sample of colorectal cancer patients. When attempting to understand colorectal cancer patients’ self-assessed work ability, return to work intentions and employment outcomes, the results suggest that perceived self-efficacy beliefs are important. Moreover, by utilising a mixed-method approach it was apparent that the role of perceived self-efficacy beliefs was diverse and somewhat complex. Results from the questionnaire study indicated longitudinal improvements in both self-efficacy domains (ability to manage cancer and job self-efficacy). However, the qualitative findings suggest that temporal fluctuations in participants’ self-efficacy beliefs were apparent. Findings suggest that whilst most expressed an intention to return to work and possessed high levels of job self-efficacy, these beliefs seemed to be overridden by barriers that included treatment type and side effects (e.g. fatigue) that appeared to result in diminished work ability. Similarly, the beneficial value of positive social support networks upon self-efficacy beliefs and subsequent work outcomes emerged from the qualitative data. The most favourable outcomes appeared to be associated with the presence of a social support network that comprised of family, friends, employers and health professionals.

The role and nature of work-related support provided by health professionals was a secondary aspect of interest to this thesis. Interviews carried out with health professionals revealed that the absence of work-related guidance was largely associated with these individuals feeling unsure about what their role should be. Consequently, this emerged as an aspect of patient care that could be improved.
In short, the findings indicate that the factors related to work ability, return to work intentions and employment status varied over time; whereby certain variables took precedence over others at particular time points. In addition, it is crucial to point out that self-efficacy is unlikely to operate as a stand-alone factor: indeed, the researcher argues that it may be a construct that is considered alongside other psychosocial factors which would inevitably help towards gaining a more comprehensive account of the factors related to the work outcomes of individuals affected by cancer.

Overall, the studies presented in this thesis allow the researcher to draw four main conclusions. Firstly, employment (work ability, job self-efficacy) and psychosocial (cancer self-efficacy, quality of life) well-being outcomes changed over time and some differences were apparent according to treatment type; secondly, factors related to and predicting work ability and employment outcomes varied over time; thirdly, temporal fluctuations in self-efficacy and the role of support were important in understanding individuals’ cancer management, return to work intentions and work ability, and finally there is a need to address the role of health professionals in providing patients with work-related support as findings suggest that these individuals may have benefited from such support. Each of the study objectives are discussed in detail below:

*Employment and Psychosocial Well-Being Outcomes over Time*

Findings from the questionnaire study showed that employment rates over the six month study duration varied in this sample of colorectal cancer patients. At baseline 24% continued to work after diagnosis; however, at follow-up time 1 this reduced to 21%; encouragingly, at follow-up time 2, 39% of participants were working. Feldman (1976) found that 68% of colon cancer patients reported an absence of nine weeks or more; in comparison, these results suggest higher absence rates with 79% reporting an absence of at least 12 weeks. By follow-up time 2, 61% reported an absence of at least 24 weeks. The reduction in employment rates between baseline and follow-up time 1 could be attributed to the onset of either chemotherapy or radiotherapy treatment. This finding is in line with prior research that has utilised a colorectal cancer sample (Sanchez et al., 2004). Sanchez and colleagues (2004) reported that
Chapter 8

Discussion

Chemotherapy treatment resulted in a delay in the resumption of work. In evaluation, earlier studies comprising colorectal cancer patients and survivors have predominantly utilised a cross sectional approach. This prospective study therefore adds knowledge to the extant literature concerned with this cancer type.

In comparison to the return to work rates reported in the general cancer and employment literature, the employment rates from this study are slightly lower. However, these colorectal participants were recruited from the point of diagnosis (post surgery but pre-chemotherapy / radiotherapy) as opposed to a number of years later (Spelten et al., 2002). Similarly, prior return to work rates are based upon samples comprised of different cancer types and varying age groups (Spelten et al., 2002; Taskila & Lindbohm, 2007; Balak et al., 2008). However, no differences according to age were apparent in this sample. Furthermore, it is reported that approximately 40% of cancer patients take time off work for treatment and recovery (Short et al., 2005), which is the more pertinent matter of interest here.

These results could partly be explained by changes in participants’ self-efficacy, work ability and psychosocial well-being over time. More importantly, results from the longitudinal questionnaire indicate that approximately six months after diagnosis colorectal cancer patients’ self-efficacy beliefs in their ability to self-manage their cancer and perform their job role are likely to improve (irrespective of treatment type). However, in spite of such positive self-efficacy levels, self-assessed work ability may prevent participants from resuming work. Decrements in work ability were found between baseline and follow-up time 1; however, between follow-up time 1 and follow-up time 2 these improved. The mean work ability value reported at six months by de Boer et al. (2008) was 4.6; considerably lower than the value of 6.22 that was found in this sample. When compared with the mean value of 5.52 reported in the gastrointestinal cancer patients, this difference is not as marked. However, this sub-sample utilised in de Boer et al’s. (2008) study was quite small (n = 23). Nevertheless, the results obtained from this sample infer that the most detrimental impact upon work ability is likely to be observed in patients undergoing either chemotherapy or
more than one treatment modality. This argument is in line with prior research (Bradley et al., 2007; de Boer et al., 2008).

Overall, the apparent disparity between self-efficacy beliefs and work ability (diary study findings) suggest that whilst some patients wished to work, they were unable to do so because their ability to perform their job role was compromised (i.e. low work ability). These findings therefore imply that for those colorectal cancer patients who possess high levels of job self-efficacy but diminished work ability, it may be worthwhile to offer temporary work adjustments (especially during treatment). Although, the practicalities of employers being able to do this, needs to be addressed. The value of providing workplace adjustments and support has been demonstrated by Pryce et al. (2007); these researchers found those receiving such support were most likely to continue with work during treatment. However, it was also reported that less than half of those that disclosed details about their cancer received workplace adjustments. Similarly, Steiner et al. (2008) did not find a difference between the level of workplace support received and workplace adjustments. These findings suggest that there may be a need to educate employers about the impact of cancer and its treatment along with the benefits of offering workplace adjustments. Such efforts could help towards improving work outcomes for both the individual affected by cancer and the organisation to which they belong.

Factors Related to Work Ability and Employment Status: The Role of Self-Efficacy

As outlined in Chapters 1 and 2, there are a number of psychosocial impacts and physical effects commonly experienced in individuals diagnosed with cancer (e.g. fatigue, poor quality of life, depressive symptoms). For this reason, these have been studied in relation to return to work and employment outcomes extensively (Feuerstein et al., 2007; Amir et al., 2008; Henry et al., 2008; Munir et al., 2009). More recently, researchers have started to investigate the impact of these factors on perceptions of work ability. Unsurprisingly, the factors related to work ability are similar to those previously identified as being related to return to work (e.g. Spelten et al., 2002; Gruber et al., 2003; Main et al. 2005;
Lee et al., 2008). As a result, the questionnaire study considered whether the impact of self-efficacy beliefs upon these outcomes could add to existing knowledge. It is acknowledged that the findings indicate that predictors and variables related to work ability and employment status are likely to alter over time; therefore, highlighting the importance of researchers adopting a longitudinal methodological approach. Factors related to perceived work ability outcomes cross-sectionally included type of occupation and quality of life at baseline, treatment type at follow-up time 1 and job self-efficacy at follow-up time 1 and 2. In contrast, factors related to employment status (i.e. working, not working) were job self-efficacy at baseline and occupation and perceived work ability at follow-up time 2. Along with self-assessed work ability at baseline, receiving chemotherapy alone or a combination of treatments (i.e. other than surgery alone) were the strongest predictors of follow-up work ability (independent of age and occupation). Finally, treatment type was also identified as the strongest predictor of employment status approximately six months after diagnosis; therefore, receiving chemotherapy alone or a combination of treatments had the significant impact on colorectal patients not going back to work.

Although job self-efficacy was not found to be significant in the longitudinal models assessing predictors of work ability and employment status, the cross sectional findings suggest otherwise. When considered along with the finding that treatment type predicted follow-up work ability and employment status most appropriately, implications for future interventions can be posited. Treatment type has been proven to be associated with work ability (e.g. Bradley et al., 2007; Taskila et al., 2007; Henry et al., 2008; de Boer et al., 2008) and employment outcomes (Taskila et al., 2007); therefore, those receiving either chemotherapy or more than one treatment modality are likely to experience a greater detriment upon their work ability and are less likely to be working when compared with those receiving surgery alone. These results suggest that this detrimental impact may be more pronounced for those possessing low self-efficacy beliefs. Indeed, Lev et al. (2001) employed a self-efficacy enhancing intervention in breast cancer patients undergoing chemotherapy that led to a decline in symptom distress and improved quality of life outcomes. Such a
technique could be used with working-aged cancer patients that could aid self-management which in turn could lead to improved work ability and better employment outcomes. In terms of practice, informing newly diagnosed working-aged patients about the potential impacts of treatment on work ability could be useful, prior to the start of treatment.

*Temporal Fluctuations and Patterns in Cancer Management, Return to Work Intentions and Work Ability: The Role of Self-Efficacy and Social Support*

Results from the diary study showed that the role of self-efficacy in the self-management of cancer and return to work intentions appeared to be more complex than the findings suggested by the questionnaire study. From the early diaries, self-efficacy levels appeared to affect participants’ return to work intentions, whereby high self-efficacy beliefs seemed to be associated with a greater desire to return to work. However, at some point during the study, all of the participants expressed an intention to return to work; findings beyond baseline suggested that this relationship was unlikely to be simplistic. Therefore, several factors seemed to impact return to work intentions and self-efficacy. Treatment (chemotherapy, fatigue and other symptoms) and decrements in perceived work ability were identified as the most prominent factors. Furthermore, the findings that treatment type and diminished work ability were commonly referred to as problematic factors corroborated the results obtained from the longitudinal questionnaire study. However, the questionnaire analyses did not identify fatigue as a factor related to (cross sectional), or, a predictor (longitudinal) of work ability or employment status. An explanation for this could be because the measure utilised to assess fatigue (Fatigue Severity Scale; Krupp et al., 1989) was not sensitive / specific enough for this patient group. Nevertheless, this finding is in line with previous research (Spelten et al., 2002; Spelten et al., 2003; Kennedy et al., 2007; Steiner et al., 2008). Follow-up diary data indicated that increased symptom burden resulted in poorer self-efficacy in ability to resume work. These participants exhibited the most temporal fluctuations in both cancer and work-related self-efficacy beliefs (self-assessment of self-efficacy varied from high-to-low). These findings therefore lend support to previous findings that a more profound
detriment is seen in those reporting more symptoms (Short et al., 2005; Bouknight et al., 2006; Taskila et al., 2007; Feuerstein et al., 2007).

These qualitative findings add to existing knowledge, particularly quantitative study results by showing that those not returning to work are not necessarily choosing this option because they do not wish to work; instead, barriers such as their treatment may be stopping them from returning. This further emphasises the importance of offering temporary work adjustments to patients who have strong intentions to return to work.

When attempting to understand how self-efficacy levels were related to return to work intentions and perceptions of work ability, social support adds another dimension to the overall picture. The presence of support appeared to enhance participants’ self-efficacy beliefs. The most favourable outcomes were seen in those who received support from a wide network comprised of family, friends, employers and health professionals. The majority received support from their employers and the support was reported as beneficial; a finding that is in line with others (Kennedy et al., 2007; Sapp et al., 2003; Michael et al., 2002; Jackson et al., 2007). Alternatively, in relation to work-related guidance, very little, or no support was received from health professionals. Within the context of this study, those not having a discussion regarding work-related matters with their health professional may have assumed that they would not be able to work. In the diaries, it was clear that most patients would have benefited from such support. Previous studies also report that cancer patients rarely discussed work issues with their health professionals (Maunsell et al., 1999; Main et al., 2005; Kennedy et al., 2007). These findings highlight the importance of considering the role of health professionals as it may be significant, particularly in relation to understanding how participants perceived their work ability.

The Need for Work-Related Advice: The Role of Health Professionals

The diary study showed that few participants received work-related guidance from a health professional associated with their care. This, along with the findings from the questionnaire study that treatment type may impact perceived work ability and subsequent employment outcomes (i.e. chemotherapy or a
combination of treatments less likely to be working) suggests that these patients may have benefited from some work-related guidance. For instance, it may have helped those with high self-efficacy and high return to work intentions but diminished work ability to discuss the possibility of temporary work adjustments during treatment with their employer.

Even though the diary study found that few patients received work-related support, the interview study suggests that health professionals are not necessarily reluctant about offering such guidance. In fact, the health professionals’ interview study identified common patterns amongst the participants. Most participants stated that they had a conversation with patients about how to manage their work most appropriately, particularly during treatment; however, this seemed to be a matter that was discussed rather fleetingly. This finding may be interpreted as encouraging as it indicates at the very least that the type of information provided at present is somewhat consistent across different health fields (e.g. oncologist to occupational health physician); however, this emerged as an aspect of patient care that was in need of improvement.

When meeting with a new working-aged cancer patient, the majority were drawing on past experiences to guide their practice and to inform the type of work-related guidance that they would provide. Irrespective of the health professional’s field, participants usually took into account the patient’s treatment, symptoms, prognosis and type of work. However, differences in health professionals’ views resulted in varied guidance; for example, the length of time deemed necessary to recover from surgery or whether a patient should work during treatment was diverse. More importantly, such differences were evident between health professionals within the same field.

Prior research has reported that patients and survivors received little or no work-related guidance from their treating health professional (Maunsell et al. 1999; Kennedy et al., 2007). In contrast, the findings generated from the interview study do indicate that health professionals try to offer work-related support and guidance, albeit limited. The findings are invaluable and add to
existing knowledge by offering explanations regarding the nature of current practice (or lack of) and potential improvements. The majority of the health professionals felt that their lack of knowledge coupled with an insufficient evidence base resulted in them being unaware of what was deemed to be the most suitable approach. Similarly, the absence of guidelines made it difficult to ascertain the level and type of guidance that should be provided to patients. This lack of clarity is concerning, particularly when some researchers have argued that with the continuity of care more specific guidance (e.g. work-related) could be possible (Verbeek et al., 2006). Moreover, when considering these findings along with those obtained from the questionnaire and diary studies, it is apparent that those receiving more than one treatment type or chemotherapy (diary study) are more likely to experience diminished work ability. Furthermore, those possessing low self-efficacy beliefs, lack of support and increased symptom burden appear to be most at risk of experiencing the most profound impact upon work ability and return to work outcomes.

Therefore, it is plausible to suggest that there is a need to address the type of support provided by health professionals.

Most importantly, the interviews yielded insightful suggestions about the possible design, structure and implementation of future intervention endeavours; hence, suggesting areas for future research especially in terms of possible pilot interventions. It was encouraging to find that the majority of participants felt that some form of intervention was required to ensure patients were provided with the most appropriate work-related guidance.

8.1. Methodological Considerations

In the review of existing literature, several limitations were identified. Previous research has utilised various cancer types or has largely considered women affected by breast cancer. Similarly, many studies have adopted a cross-sectional design which renders it difficult to map factors predicting employment outcomes over time. The importance of adopting a prospective design are reflected by the findings presented within this thesis; whereby the factors related to work ability and employment status were found to vary over the six month period. In addition, only a small number of findings are based on a
sample of cancer patients or survivors from the UK and little is known about those diagnosed with colorectal cancer. Further to this, a degree of inconsistency regarding the assessment of work ability was inherent (Taskila et al., 2007). Whilst this study has its strengths in that it attempted to address these prior limitations, it is not without its own weaknesses. Participants were recruited via NHS Trusts or a support group. Not all cancer patients utilise support groups, thus it is difficult to ascertain the extent to which these results are reflective of all colorectal cancer patients. Similarly, it was not possible to compare the demographic and cancer-related information of those who were successfully recruited from the NHS Trusts and those who chose not to participate. It is also acknowledged that those choosing to participate may have already possessed high levels of self-efficacy, hence, leading to the problem of self-selection bias. However, the diary study found self-efficacy fluctuated temporally, even in those who exhibited high levels at baseline; more pronounced changes were apparent in individuals undergoing chemotherapy treatment.

When considering the study sample further, it is noted that the absence of a disease-free, working-age comparison group renders it difficult to determine whether changes in self-efficacy, work ability and employment status were exclusively attributable to cancer and its treatment. In addition, the absence of a control group makes it difficult to ascertain whether scores assessed by the questionnaire regressed toward the mean (Shaughnessy & Zechmeister, 1990). Nonetheless, recruiting patients was a challenge for the researcher as resources were limited. It could be argued that the most useful approach to improve sample size, overall research design and reliability would be to develop a nationwide multi-disciplinary team. This concerted effort would allow data to be collected from a greater number of NHS Trusts; furthermore, this would also be the most appropriate route for implementing future interventions. Inevitably, this would facilitate a greater understanding into how cancer patients manage their treatment and work.

Overall, the scales utilised to measure the various dimensions of psychosocial well-being (fatigue, depression, quality of life, cancer self-efficacy) and work-
related factors (work ability and job self-efficacy) were robust and validated; however, certain scales may have lacked a degree of specificity when applied to the colorectal cancer sample. For example, some of the items that comprised the Beck Depression Inventory (Beck et al., 1996) may have been a side effect of chemotherapy treatment (e.g. items related to tiredness and lack of energy) rather than a depressive symptom per se. Similarly, in hindsight, the measure used to assess fatigue (Fatigue Severity Scale; Krupp et al., 1989) may have been too generic in nature. In addition, correlations between some of these measures indicate that a level of common variance may have been inherent; for example, the quality of life (FACT-G; Cellar et al., 1993) and depression (BDI; Beck, 1972) measures were significantly correlated at both follow-up time 1 and time 2 (r = -0.82; r = -0.80), thus, raising the issue of duplication. However, such measures have previously been adopted in studies utilising cancer samples. Furthermore, it was important not to place an unnecessary burden on participants; therefore, an effort was made to keep scales (i.e. length) minimal: this may have helped to maintain participation (one participant withdrawal) over the study duration. The measure used to assess job self-efficacy was a modified version of a return to work self-efficacy scale designed for those with back pain (Shaw & Huang, 2005). Even though this measure was found to be related to work ability and employment status cross-sectionally, it was not significant in the prospective models. It would be useful to follow-up these patients post-treatment to see whether this would alter. Alternatively, it may be worthwhile to design a cancer specific job self-efficacy scale.

8.2. Implications of Findings and Future Directions

Undoubtedly, the implications of these findings suggest that self-efficacy warrants further investigation in this area of research. Indeed, it is not being proposed that self-efficacy be considered alone in future research; instead, it is a factor that needs to be studied alongside pre-existing ones such as treatment type and fatigue that have previously been found to impact work ability, return to work and employment outcomes. Furthermore, there is a need to consider self-efficacy beliefs in other cancer groups as these findings may not be reflective of the general cancer population. Additionally, this would enable any differences
to be mapped. Alternatively, these results do implicate the role of treatment as perhaps being of more importance than cancer type itself. However, this is a matter that needs to be addressed in future research endeavours.

Self-efficacy beliefs are argued to be amenable to change (Lev et al., 2001). Interventions incorporating self-efficacy enhancing techniques could prove beneficial especially for patients whose treatment is multi-faceted or those who experience a greater degree of symptom burden. This is because these results indicate that these individuals are likely to encounter the most detrimental impact in terms of their work ability. Consequently, researchers need to find a way to minimise this impact. The findings showed that self-efficacy beliefs improved over time; therefore, it could be argued that offering some form of guidance would be most beneficial at an early stage. Further to this, the diary study results imply that the presence of support could also enhance self-efficacy beliefs.

Based upon the diary study results, it seemed appropriate to recommend that support in the form of advice or guidance could be provided in a rather generic form at the outset. Tailored support could then be provided based upon the specific needs of the individual, such as their perceived self-efficacy (to manage cancer and return to work), work ability and type of job once treatment, particularly chemotherapy has commenced. However, it has been suggested that doctors may find this difficult to carry out (Mock, 1998). This is further supported by the findings that emerged from the health professionals’ interview study. These participants indicated that the most effective strategy would be one that involved various health professionals as opposed to a particular individual being allotted the role. Subsequently, the most useful approach is likely to include the general practitioner, consultant surgeons, consultant oncologist, specialist nurses and where possible an occupational health professional. However, prior to the implementation of an intervention, it is necessary to formulate guidance for health professionals to ensure consistent work-related support is provided to those that are in employment at diagnosis. Future research could therefore involve carrying out two studies with health professionals that would help to identify aspects to be included in any given
guidance. Firstly, a questionnaire could be designed and completed by a variety of health professionals that are most likely to be involved in a cancer patient’s care (consultant surgeons, oncologists, specialist nurses, general practitioners, occupational health professionals). Secondly, for more in-depth data a sub-sample could participate in a semi-structured interview. To further ensure that the correct guidance is provided to health professionals, cancer patients and survivors could be interviewed to explore the most useful type of support (i.e. information) that could be provided. Additionally, incorporating the patient and their employer in the overall management of work and cancer was deemed to be important. From patients’ point of view, having a discussion regarding work ability during and after cancer treatment could facilitate better management of their work. Similarly, the diary study highlighted that the involvement of the employer is also important. It was apparent within this sample that participants wished to return to work. However, reduced self-efficacy in ability to perform their job and treatment was preventing a return. In response, employers (especially those without a return to work policy) could be educated and trained on how to manage an employee with cancer and to facilitate work adjustments where possible. Future research could involve interviewing employers to identify where gaps in knowledge may lie. This could then lead to a brief leaflet or tool being developed that details how certain treatments may impact employees and how a return to work could be managed.

8.3. Conclusion

The data collected from this study provides an account of how colorectal cancer patients manage their disease and work from the point of diagnosis and during treatment. The role of self-efficacy, to the researcher’s knowledge, has not previously been considered in this area. Despite the sample being relatively small, the longitudinal nature of the overall study and the results obtained indicate the richness of the data collected. Furthermore, adopting a mixed-methodological approach allowed for a more comprehensive understanding of the temporal changes and patterns in self-efficacy, work ability, return to work intentions and employment outcomes to be identified in this group.
In sum, the findings provide invaluable knowledge about how colorectal cancer patients’ self-efficacy beliefs impact work ability, return to work intentions and employment status. Furthermore, the findings from the study indicate that predictors and variables related to work ability and employment status are likely to alter over time. Over a six month period, cancer self-efficacy and job self-efficacy were found to improve over time. Closer examination of changes in job self-efficacy according to treatment group suggested that compared with those receiving surgery alone, those receiving chemotherapy or more than one treatment type showed a decline in scores between baseline and follow-up time one. However, this group difference was not statistically significant. Despite this, it should not go unnoticed as it identifies a possible point at which patients could be offered support (e.g. guidance about treatment effects in relation to work outcomes). This is further supported by the work ability findings, whereby, a significant time x treatment type effect was found. Furthermore, treatment type was also identified as a predictor of follow-up work ability and employment status; those receiving chemotherapy alone or a combination of more than one treatment type were most likely to report worse work ability and were less likely to be working at follow-up. The diary study findings yielded results that were further insightful. In particular, it was apparent that most participants displayed high self-efficacy levels in relation to managing their work and expressed an intention to return to work; however, barriers were apparent: notably cancer treatment and treatment effects often led to diminished work ability which seemed to prevent patients resuming work. Based upon these findings, it is plausible to suggest that it would be useful to provide colorectal cancer patients and perhaps cancer patients in general with information about the impact of cancer and its treatment on work ability. Whilst, the diary study identified that only a few participants received verbal work-related guidance or information from their treating health professional, the health professionals’ interview study suggested that the majority felt this was an aspect of patient care that needed to be addressed.

Moreover, the results in their entirety suggest that patients, who undergo more than one treatment modality, report the most symptom burden and have poor social support networks are most at risk of reporting worse work ability and work
outcomes. Furthermore, this unfavourable impact is likely to be even more pronounced in those possessing low levels of self-efficacy. Consequently, it is important to work towards ensuring that these individuals especially are provided with information and guidance (e.g. from a health professional) so that they are aware of the potential impacts of cancer and its associated treatments. However, prior to developing any form of intervention for patients, researchers need to address the lack of knowledge found to be inherent among health professionals. Developing some form of guidance for health professionals regarding the impacts of cancer upon work ability and employment outcomes would essentially ensure that patients are provided with a consistent level of work-related guidance. Therefore there is much scope to develop interventions for the patients themselves and guidance for healthcare professionals and the employment sector to ensure that the necessary support and information is provided to working-aged patients.
References


American Cancer Society. (2000). *Smoking linked to increased colorectal cancer risk – new study linked to increased colorectal cancer risk*. Available at [http://www.cancer.org/docroot/NWS/content/NWS_1_1x_Smoking_Linked_to_Increased_Colorectal_Cancer_Risk.asp](http://www.cancer.org/docroot/NWS/content/NWS_1_1x_Smoking_Linked_to_Increased_Colorectal_Cancer_Risk.asp) Accessed 8 January 2008.


Cancer Research UK. (2005a). *Breast Cancer: Breast cancer survival statistics*. Available at...


References


Appendices

**The TNM Staging System**

Tumour size (T) is staged as follows:

- **T1** – The tumour is contained within the inner lining of the bowel wall.
- **T2** – The tumour has grown into the muscle layers of the bowel wall.
- **T3** – The tumour has grown through the membrane covering the outside of the bowel.
- **T4** – The tumour has expanded into other parts of the body that are located nearby to the bowel.

Subsequently, lymph node (N) involvement is categorised as follows:

- **N0** – No lymph nodes contain cancer cells.
- **N1** – 1-3 lymph nodes contain cancer cells.
- **N2** – 4 or more lymph nodes contain cancer cells, which are more than 3cm away from the primary tumour (Cancer Research UK, 2002).

The degree of metastasis (M) is staged in two ways:

- **M0** – The cancer has not spread to any other part of the body.
- **M1** – The cancer has spread to other parts of the body.

Therefore, once the cancer has been categorised according to the above it is assigned one of the following stages:

- **Stage 0** – The cancer cells are confined to the lining of the bowel.
- **Stage 1** – Cancer cells are present in the inner lining of the bowel, or have grown into the muscle layer of the bowel. However, cancer cells are not present in the lymph nodes (T1, N0, M0 or T2, N0, M0).
- **Stage 2** is divided into:
Stage 2a – The cancer has passed through the outer membrane of the bowel. However, the lymph nodes do not contain cancer cells (T3, N0, M0).

Stage 2b – The cancer has passed through the membrane covering the bowel wall into surrounding tissues / organs nearby. There is no lymph node involvement or metastasis (T4, N0, M0).

- Stage 3 is divided into:
  - Stage 3a – The cancer cells are contained within the inner layer of the bowel, or have grown into the muscle layer. In addition, between 1 and 3 lymph nodes nearby contain cancer cells (T1, N1, M0 or T2, N1, M0).
  - Stage 3b – The cancer has passed through the bowel wall, or surrounding tissues / organs. In addition, between 1 and 3 lymph nodes nearby contain cancer cells (T3, N1, M0 or T4, N1, M0).
  - Stage 3c – The cancer can be of any size, spread to 4 or more lymph nodes. However, there is no metastasis (anyT, N2, M0).

- Stage 4 – The cancer has spread to other parts of the body (anyT, anyN, M1).
17 December 2007

Dr F Munir
Lecturer and PhD Supervisor
Loughborough University
Loughborough
Leicestershire
LE11 3TU

Dear Dr Munir,

Full title of study: Employment decisions of cancer patients: An examination of the psychosocial and work-related factors associated with continued employment and return to work.

REC reference number: 07/H0408/158

Thank you for your letter of , responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Application</td>
<td>AB/112069/1</td>
<td>31 October 2007</td>
</tr>
<tr>
<td>Investigator CV - CI</td>
<td></td>
<td>31 October 2007</td>
</tr>
</tbody>
</table>

This Research Ethics Committee is an advisory committee to East Midlands Strategic Health Authority. The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England.
Appendix 2

<table>
<thead>
<tr>
<th>Investigator CV</th>
<th>31 October 2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>Investigator CV - Supervisor</td>
<td>31 October 2007</td>
</tr>
<tr>
<td>Protocol</td>
<td>12 December 2007</td>
</tr>
<tr>
<td>Summary/Synopsis</td>
<td>31 October 2007</td>
</tr>
<tr>
<td>Letter from Sponsor</td>
<td>25 October 2007</td>
</tr>
<tr>
<td>Statistician Comments</td>
<td>01 November 2007</td>
</tr>
<tr>
<td>Questionnaire: 8a</td>
<td>12 December 2007</td>
</tr>
<tr>
<td>Questionnaire: 8b</td>
<td>12 December 2007</td>
</tr>
<tr>
<td>Questionnaire: 8c</td>
<td>12 December 2007</td>
</tr>
<tr>
<td>Questionnaire: 8d</td>
<td>12 December 2007</td>
</tr>
<tr>
<td>Questionnaire: 8e Diary Sheet</td>
<td>12 December 2007</td>
</tr>
<tr>
<td>Letter of invitation to participant</td>
<td>31 October 2007</td>
</tr>
<tr>
<td>Participant Information Sheet</td>
<td>12 December 2007</td>
</tr>
<tr>
<td>Participant Consent Form</td>
<td>12 December 2007</td>
</tr>
<tr>
<td>Response to Request for Further Information</td>
<td>12 December 2007</td>
</tr>
<tr>
<td>Diagram of Protocol in Non-Technical Language</td>
<td>12 December 2007</td>
</tr>
<tr>
<td>Statement of Indemnity Arrangements - Professional</td>
<td>01 August 2007</td>
</tr>
<tr>
<td>Statement of Indemnity Arrangements - Employers Liability / Public &amp; Products</td>
<td>01 August 2007</td>
</tr>
</tbody>
</table>

R&D approval

All researchers and research collaborators who will be participating in the research at NHS sites should apply for R&D approval from the relevant care organisation, if they have not yet done so. R&D approval is required, whether or not the study is exempt from SSA. You should advise researchers and local collaborators accordingly.


Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

Here you will find links to the following:

a) Providing feedback. You are invited to give your view of the service that you have received from the National Research Ethics Service on the application procedure. If you wish to make your views known please use the feedback form available on the website.

b) Progress Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.

c) Safety Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.

d) Amendments. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
e) End of Study/Project. Please refer to the attached Standard conditions of approval by Research Ethics Committees.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nationalres.org.uk.

07/H0408/158 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Dr M Hewitt / Ms L Ellis
Chair / Coordinator

Email: Linda.ellis@nottspct.nhs.uk

Enclosures:
Standard approval conditions

Copy to:
Mr P Townsend
Research Manager
Loughborough University
Leicestershire LE11 3TU
LOUGHBOROUGH UNIVERSITY
ETHICAL ADVISORY SUB-COMMITTEE

RESEARCH PROPOSAL
INVOLVING HUMAN PARTICIPANTS

Title: Employment decision of older cancer patients: An examination of the psychosocial, social and work-related factors associated with continued employment and return to work

Applicant: Dr M Fehmidah, M Bains

Department: Human Sciences

Date of clearance: 13 April 2007

Comments of the Sub-Committee:
The Sub-Committee agreed to issue clearance to proceed subject to certain conditions which have since been met by the investigators.

Miss Meredith Lee BA (Hons), MSc
Assistant Secretary
Loughborough University Ethical Advisory Committee
Heart of England
NHS Foundation Trust

Birmingham Heartlands Hospital
Bordesley Green East
Birmingham B9 5SS
Tel: 0121 424 2000
Fax: 0121 424 2200

Research & Development Directorate
Heartlands Research & Innovation Unit
Lincoln House
Office Hours (Mon-Fri): 09.00 – 17.00
Tel: 0121 424 1635 (Projects)
Fax: 0121 424 2345

R & D Manager: Bethan Bishop
Research Governance Manager: Elizabeth Adey
R & D Finance Manager: Rachel Ward
Please send e-mails via firstname.surname@heartofengland.nhs.uk

12 February 2008

Ms M. Bains
PhD Research Student
Department of Human Sciences
Loughborough University

Dear Ms Bains

Re: R&D project code 2007STU003.EXT
Managing Cancer & Employment – Employment decision of cancer patients: an examination of the psychosocial and work-related factors associated with continued employment and return to work

I am pleased to inform you that the R&D review of the above project is now complete and has been formally approved to be undertaken at Heart of England NHS Foundation Trust. The following documents were reviewed:

Protocol: V2.0 12 December 2007
PIS & Consent: V2.0 12 December 2007
GP letter: N/A
NHS NRES Application Form Dr F. Munir 02 November 2007
NRES Site Specific Information Form M. Bains 31 October 2007
NRES Approval Letter 17 December 2007
SSI Approval Letter SSA Exempt
Other documents (please specify):
Statement of Indemnity Arrangements (professional): 01 August 2007
Statement of Indemnity Arrangements (employer liability/public & products) 01 August 2007

The conditions of this approval are as follows:

1) You adhere to the approved version of the protocol and notify R&D immediately of any changes to the study, including any new staff working on the project, who may need Trust or Honorary contracts issued.
2) You notify R&D of any Serious Adverse Events
3) You adhere to the requirements of the ethics committee as detailed in their approval letter and standard operating procedures which can be found on www.nresform.org.uk.
4) You notify R&D on completion of the project

... continued ...
Appendix 2

The duration of this approval extends to the date specified in the COREC ethics application form, except where action is taken to suspend or terminate the opinion or should your research not begin within 2 years of the approval date.

Should your study require the dispensing of drugs, please allow 2 weeks from the date of this approval letter (or earlier with the prior agreement from the clinical trial pharmacy team) before drug release, to allow the department to be ready for the receipt of drug supplies.

May I also draw your attention to the Research Governance Framework which can be found on the internet http://www.dh.gov.uk/assetRoot/04/10/89/65/04108965.pdf and remind you that all research within the Trust should be run to the standards as outlined in this document. Guidance and advice is always available from the Department of Research and Development should you require it at any stage of your project.

If you have any queries please do not hesitate to contact me.

Yours sincerely

[Signature]

Liz Adey
Research Manager (Governance & Operations)
Miss M Bains  
Department of Human Sciences  
LE11 3TU

01 April 2008

Dear Miss Bains

ID: 07ON029

Employment decisions of cancer patients: An examination of the psychosocial and work-related factors associated with continued employment and return to work.

The R&D Department has considered the following documents:

- NRES Application forms
- Protocol, version 2 dated 12/12/07
- Letter of invitation to participant version 1 dated 31/10/07
- Participant information Sheet version 2 dated 12/12/07
- Participant Consent Form, version 2 dated 12/12/07

Your study now has R&D approval, on the understanding and provision that you will follow the conditions set out below.

Conditions of Approval

That you:

1. Accept the responsibility of Chief/Principal Investigator as defined in the current Research Governance Framework.
2. Request written approval from the R&D department for any change to the approved protocol/study documents you wish to implement
3. Ensure all study personnel, not employed by the Queens Medical Centre, University Hospital NHS Trust Nottingham or the City Hospital NHS Trust Nottingham, hold honorary Contracts with this Trust, before they have access to any facilities, patients, staff, their data, tissue or organs.
4. Report any Serious Adverse Event involving the Trust to the R&D department, using the Trust 'policy for research safety reporting in human subjects'. Policy available from the R&D Department.
5. Complete the R&D Research Governance interim and final reports as requested.
6. Comply with the regulatory requirements and legislation relating to: Data Protection, Trust Caldicott Guidelines, Health and Safety and the use of Human Tissue for research purposes.
8. Agree to conduct this research project in accordance with ICH Good Clinical Practice and/or the MRC Guidelines for Good Clinical Practice (as appropriate)
9. Must not start your project until you have received written approval from the relevant ethics committee.

Please note that the R&D department has a database containing study related information, and personal information about individual investigators e.g. name, address, contact details etc. This information will be managed according to the principles established in the Data Protection Act.
20/02/2009

Professor Will Steward
Department of Cancer Studies and Molecular Medicine
Level 2, Osbourne Building
Leicester
Leicester General Hospital
LE1 5WW

Dear Professor Will Steward

Ref: UHL 10642

Title: Employment decisions of cancer patients: An examination of the psychosocial and work-related factors associated with continued employment and return to work.

Project Status: Project Approved
End Date: 01/01/2009

I am pleased to confirm that with effect from the date of this letter, the above study now has Trust Research & Development permission to commence at University Hospitals of Leicester NHS Trust.

All documents received by this office have been reviewed and form part of the approval. The documents received and approved are as follows:

<table>
<thead>
<tr>
<th>Document Name</th>
<th>Version Number</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Application</td>
<td>AB/112069/1</td>
<td>31.10.2007</td>
</tr>
<tr>
<td>Protocol</td>
<td>3</td>
<td>23.07.2008</td>
</tr>
<tr>
<td>Summary/Synopsis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Letter from Sponsor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Statistician Comments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Questionnaire: 8a</td>
<td>2</td>
<td>12.12.2007</td>
</tr>
<tr>
<td>Questionnaire: 8b</td>
<td>2</td>
<td>12.12.2007</td>
</tr>
<tr>
<td>Questionnaire: 8c</td>
<td>2</td>
<td>12.12.2007</td>
</tr>
<tr>
<td>Questionnaire: 8d</td>
<td>2</td>
<td>12.12.2007</td>
</tr>
<tr>
<td>Questionnaire: 8e Diary Sheet</td>
<td>2</td>
<td>12.12.2007</td>
</tr>
<tr>
<td>Document Description</td>
<td>Quantity</td>
<td>Date</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------------------</td>
<td>----------</td>
<td>------------</td>
</tr>
<tr>
<td>Letter of Invitation to Participant</td>
<td>1</td>
<td>31.10.2007</td>
</tr>
<tr>
<td>Participant Information Sheet</td>
<td>3</td>
<td>23.07.2008</td>
</tr>
<tr>
<td>Participant Consent Form</td>
<td>2</td>
<td>12.12.2007</td>
</tr>
<tr>
<td>Statement of Indemnity Arrangements - Professional</td>
<td></td>
<td>01.08.2007</td>
</tr>
<tr>
<td>Statement of Indemnity Arrangements - Employers Liability / Public &amp; Products</td>
<td></td>
<td>01.08.2007</td>
</tr>
<tr>
<td>Questionnaire: Colorectal Cancer and Return to Work: Questionnaire ASSESSMENT 2</td>
<td>1</td>
<td>23.07.2008</td>
</tr>
<tr>
<td>Questionnaire: Colorectal Cancer and Return to Work: Questionnaire ASSESSMENT 1</td>
<td>1</td>
<td>23.07.2008</td>
</tr>
<tr>
<td>An Employer's Tool for Managing an Employee with Colorectal Cancer</td>
<td>1</td>
<td>23.07.2008</td>
</tr>
<tr>
<td>Managing Colorectal Cancer and your work (intervention leaflet)</td>
<td>1</td>
<td>23.07.2008</td>
</tr>
<tr>
<td>Non-Substantial Amendment</td>
<td></td>
<td>10.02.2009</td>
</tr>
<tr>
<td>CV/GCP: Edwina Scott</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CV/GCP: Joanna Wood</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CV/GCP: Victoria Brown</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please be aware that any changes to these documents after approval may constitute an amendment. The process of approval for amendments should be followed. Failure to do so may invalidate the approval of the study at this trust.

We are aware that undertaking research in the NHS comes with a range of regulatory responsibilities. Attached to this letter is a reminder of your responsibilities during the course of the research. Please ensure that you and the research team are familiar with and understand the roles and responsibilities both collectively and individually.

You are required to submit an annual progress report to the R&D Office and to the Research Ethics Committee. We will remind you when this is due.

The R&D Office is keen to support research, researchers and to facilitate approval. If you have any questions regarding this or other research you wish to undertake in the Trust, please contact this office.

We wish you every success with your research.

Yours sincerely,

Carolyn Burden
R&D Manager

Encs: Project Information Sheet.
Participant Invitation Letter

Dear Patient / Sir / Madam,

We would like to let you know about a research study that is being undertaken in our Colorectal Department by Miss Manpreet Bains, who is a research student undertaking a PhD in Managing Cancer and Employment at Loughborough University.

The proposal has been approved by the Research and Development office at this Hospital, and has also been approved by the Research Ethics Committee.

Miss Bains would greatly appreciate any help you are able to offer with this study, which aims to look at the management of cancer, and the effect this has on a person’s ability to work.

Participating in this research project does not form part of your clinical treatment, but it will give you the opportunity to discuss how you manage your illness and work (if employed). Choosing not to participate in this study, or withdrawing from the study at any stage, will not affect your treatment in any way. If you do decide to take part all information collected during the course of the study will be kept strictly confidential.

Further details are given in the attached information sheet. If you are interested in taking part, or would like some more information contact Miss Bains directly (Tel: 01509 228152 E-mail: M.Bains@lboro.ac.uk).

Yours faithfully

Consultant Surgeon
Research Participant Information Sheet

Managing Cancer and Employment

- Approximately 40% of all cancer patients take time off work during treatment and recovery.
- Return to work rates in cancer patients range from 30-93%.
- Why do some people choose to stop working whilst others continue?
- How confident do you feel about managing your illness and your work?

We are running a study to look at the management of cancer, and the effect this has on ability to work. We are interested in hearing from people who work full or part-time or are on sick leave.

You are being invited to take part in a research study. Before you decide it is important for you to understand why it is being carried out and exactly what is involved. Please take your time to read through the following information carefully. If anything is unclear please do not hesitate to get in touch with us for more information.

1. What is the purpose of the study?
The purpose of the study is to investigate cancer patients’ experiences in managing cancer. Evidence suggests this age group is more likely to take time of sick, and less likely to return to work. Past research tells us for some cancer patients returning or continuing with work is straightforward, however, for others it can be challenging. We want to know whether you are currently employed (full or part-time) or on sick leave, and how cancer may have impacted your working life. We also want to know how confident you are feeling about managing your symptoms and illness.

2. Why have I been chosen?
We would like to gain an insight into whether cancer patients continue to work, take sick-leave, leave work, or retire after diagnosis. This will help us to better understand the needs of this group. We are interested in your views on your health, your work and work environment (if you are working) and your feelings towards managing your health and work effectively. We have chosen to include people who meet the following criteria:

1. Be in employment at the time of diagnosis (including those currently on sick-leave) (≥18.5 hours per week).
2. Diagnosed with colorectal cancer.
3. Provide written informed consent.
4. Have a permanent address or contact details.

3. Do I have to take part?
Whether or not you decide to take part is entirely up to you. If you do decide to take part, you may keep this information sheet and you will be asked to read and complete a consent form. If you decide to take part you have the right to withdraw from the study at any time without giving us a reason. Choosing not to participate in this study, or withdrawing from the study at any stage, will not affect your treatment/standard of care in any way.

4. What do I have to do?
- If you would like to participate you will be asked to complete a consent form.
- After this you will be asked to complete a questionnaire.
• The questionnaire will ask you about your health and whether or not you are working. The questionnaire will ask you about any concerns you may have about your health and your work (if you are working).
• To monitor any changes in your health and work, this same questionnaire will be sent to you again three months later, and if appropriate six months later.
• You will also have the opportunity to complete a monthly diary, which is optional. This will ask you about your feelings of confidence in managing your symptoms, diet, activities, cancer and work (if you are working).
• We will provide you with stamped-addressed envelopes to return all study materials to us.

5. What are the possible disadvantages and risks of taking part?
The areas covered in the questionnaire and diary booklet are not designed to cause you any distress. However, we acknowledge that some people may view them as being sensitive. We would like to reassure you that the necessary measures will be put in place to deal with this should it occur. Your clinician and nurse will be briefed if you take part. In addition, if you feel distressed at any point you can contact Cancerbackup (0808 800 1234), or your Patient Advice and Liaison Service (PALS). It may be one of your concerns that your confidentiality might be at risk if you do discuss personal experiences. We would like to reassure you that taking part will be completely confidential. We would like to reassure you that you can withdraw from the study at any point without providing us with a reason. Your welfare and well-being is of key importance, and we would retain this thought throughout the study period.

6. What are the possible benefits of taking part?
Participating in this research project will give you the opportunity to discuss how you manage your illness and work (if employed). By gathering information on your thoughts and experiences we aim to be in a position to design interventions to help people like you better manage cancer and employment. With this information we can work with organisations and healthcare professionals to ensure that the necessary support and information is given to working-aged patients. With your help we hope to highlight the barriers that may be preventing some individuals from continuing with/or returning to work.

7. What happens when the research study stops?
The principal investigator (Manpreet Bains) will write up the results of the study and discuss the implications of the findings with staff in the Human Sciences Department at Loughborough University. A summary of the findings and the associated guidance will be provided to both you and your NHS Trust.

8. Will my taking part in this study be kept confidential?
We aim to ensure anonymity of participants at all times. All information that is collected about you during the course of the study will be kept strictly confidential. Any quotations utilised from your comments and findings will be presented anonymously. All consent forms will be separated from the responses on receipt of the questionnaire by the research team. The study will comply with the Data Protection Act of 1998.

9. What will happen to the results of the research study?
The results will be held on a personal computer until the project is complete. The principal investigator (Manpreet Bains), Dr Fehmidah Munir (chief investigator and project supervisor) and Dr Joanna Yarker (co-supervisor) are the only people that will have access to the results. If the study is successful and put forward for publication, we will ensure that the presentation of any results will not identify any individual’s details.
10. **Who is organising and funding the research?**
The research is being organised by Miss Manpreet Bains and Dr Fehmidah Munir at Loughborough University, and Dr Joanna Yarker at Goldsmiths College, London.

11. **Who has reviewed the study?**
This study has been reviewed and given a favourable ethical opinion for conduct by an NHS Research Ethics Committee and Loughborough University’s Ethical Advisory Committee.

12. **What if something goes wrong?**
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 and should consult a solicitor specialising in clinical negligence. Regardless of this, if you wish to complain 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 may be available to you. The Patient Advice and Liaison Service at are available to help if you have any concerns, or require advice: (Birmingham – (0121) 424 1212; Nottingham - (0115) 9249924 ext 64924)

13. **Contact for further information**
If you require more information, or wish to take part in this study please contact:

**Miss Manpreet Bains, Principal Investigator.**
PhD Research Student. BSc (Hons). MSc. Health Psychology.

Department of Human Sciences
Loughborough University
Loughborough
Leicestershire
LE11 3TU

Email: M.Bains@lboro.ac.uk
Tel: 01509 228152

*Thank you for taking the time to read this information sheet.*

If you have any queries please contact:

**Manpreet Bains** (Principal Investigator) **Tel:** 01509 228152
**E-mail:** M.Bains@lboro.ac.uk or **Dr Fehmidah Munir** (Chief Investigator) **Tel:** 01509 228228
**E-mail:** F.Munir@lboro.ac.uk
# RESEARCH PARTICIPANT CONSENT FORM

**MANAGING CANCER AND EMPLOYMENT**

(Please circle)

1. Have you read the participant information sheet (version 2, 12/12/2007)?
   - YES/NO

2. Have you had the chance to discuss this study and ask questions about it?
   - YES/NO

3. Have you had the satisfactory answers to all your questions?
   - YES/NO

4. Have you been given enough information about the study?
   - YES/NO

5. Who has explained the study to you? .................................................................YES/NO

6. Do you understand that you are under no obligation to take part in the study? YES/NO

7. Do you understand that you are free to withdraw from the study?
   - At any time?
   - Without having to give a reason?
   - Without affecting your future medical care?
     - YES/NO

8. Do you understand that all information that you provide will be treated as STRICTLY CONFIDENTIAL?
   - YES/NO

9. Do you understand that any material used in project reports and academic papers will be used anonymously and will not identify you in any way?
   - YES/NO

10. Do you give permission for the researcher to contact a colorectal nurse if they become concerned for your well being?
    - YES/NO

11. I understand that sections of any of my research records may be looked at by responsible individuals from regulatory authorities or from the NHS Trust where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.
    - YES/NO

12. Have you had enough time to come to a decision?
    - YES/NO

13. Do you agree to take part in this study?
    - YES/NO

- Would you like to participate in the diary element of the study?
  - YES [ ]
  - NO [ ]

<table>
<thead>
<tr>
<th>Participant Name:</th>
<th>Date:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address:</td>
<td>E-mail:</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Participant Signature:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Investigator Signature:</th>
</tr>
</thead>
</table>
Managing Cancer and Employment: Background Questionnaire

Part 1: About you

The following questions are confidential; answers will not be used to identify individuals. This information is very useful as it will help us look for patterns among cancer patients. Please tick or write the answer that best applies to you in the space provided.

1. Gender:
   - Male [ ]
   - Female [ ]

2. Date of Birth: ______________

3. Ethnicity: (please choose one section from a) to e) and then tick the box that best applies to you).

   a) White
      - British [ ]
      - Irish [ ]
      - Any other white background [ ]

   b) Mixed
      - White and Black Caribbean [ ]
      - White and Black African [ ]
      - White and Asian [ ]
      - Any other mixed Background [ ]

   c) Asian or Asian British
      - Indian [ ]
      - Pakistani [ ]
      - Bangladeshi [ ]
      - Any other Asian Background [ ]

   d) Black or Black British
      - Caribbean [ ]
      - African [ ]
      - Any other Black Background [ ]

   e) Chinese or other ethnic group
      - Chinese [ ]
      - Any other ethnic group [ ]

4. Please indicate below your height and weight. Please circle measurement used.

   Height: ______________ feet/inches or metres
   Weight: ______________ Stones/lbs or kilos
5. Education level (please tick the box next to your highest qualification)

None ☐ Degree ☐
GCSE (or equivalent) ☐ Higher Degree (MSc, MA, PhD) ☐
AS Level (or equivalent) ☐

Part 2: About your work

6. How would you describe your current employment status?

Working full-time ☐ On sick leave ☐ Incapacity Benefit ☐
Working part-time ☐ Unemployed ☐ Retired ☐

7. What is/was your occupation?

8. How long have you/did you work in this role?

______________ Years ____________ Months

9. Do you/did you do shift work or regular hours?

Shift work ☐ Regular hours ☐

10. What sort of employment contract do you/did you have?

Permanent ☐ Fixed-term ☐

11. Approximately how many people are/were employed by your organisation?

1-10 employees ☐ 50-199 employees ☐ 1000+ employees ☐
11-49 employees ☐ 200-1000 employees ☐ Not applicable ☐
Self employed ☐

12. Salary: (please tick the box that best applies/applied to you)

Up to £15,000 ☐ £21,100 - £25,000 ☐ £34,100 - £45,000 ☐
£15,100 - £21,000 ☐ £25,100 - £34,000 ☐ Above £45,100 ☐

Part 3: About your condition

13. What type of cancer do you have? ☐

14. When were you diagnosed?

__________________________ Year __________________ Month

15. What is the severity of your condition (stage and grade)?

________________________________________ Don’t know ☐
16. Please complete the table below about the treatments you are receiving/have already received (please circle all that apply).

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Receiving</th>
<th>Frequency</th>
<th>Complete</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgery</td>
<td>Yes</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td></td>
<td>No</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>Yes</td>
<td>Daily</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>Weekly</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Monthly</td>
<td></td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>Yes</td>
<td>Daily</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>Weekly</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Monthly</td>
<td></td>
</tr>
<tr>
<td>Other (Please specify)</td>
<td></td>
<td>Daily</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Weekly</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Monthly</td>
<td></td>
</tr>
</tbody>
</table>

17. Have you been diagnosed with cancer in the past?
Yes [ ]
No [ ] (Please go to Q38)

18. What type(s) of cancer(s) were you diagnosed with and when?
1. [Date]
2. [Date]
3. [Date]

19. What type(s) of treatment(s) did you receive? Please tick the appropriate boxes.

<table>
<thead>
<tr>
<th>Treatment</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgery</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiotherapy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hormone Therapy</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

20. Do you currently have any other chronic or life threatening diseases?
Yes [ ] (Please specify)
No [ ]

21. Are you currently receiving any other treatment(s) for any other conditions?
Yes [ ] (Please specify)
No [ ]

Thank you for taking the time to complete this questionnaire!
Managing Cancer and Employment: Questionnaire Assessment 1

Today’s date:

Why is this research important?

We would like to gain an insight into the employment decisions of cancer patients. We are interested in your views on your health, your work and your feelings towards managing your health and work effectively.

By gathering information on your thoughts and experiences we aim to be in a position to design interventions to help people like you better manage cancer and employment. With this information we can work with organisations and healthcare professionals to ensure that the necessary support and information is given to working-aged patients.

What do I have to do?

Completion of this confidential questionnaire is entirely voluntary, but we would be grateful for your help with this study because your contribution can make a big difference. The questionnaire overleaf should take approximately 30 minutes to complete. There are three sections to this questionnaire:

- **Section A** is to be completed by all participants
- **Section B** is to be completed only by those who are currently working
- **Section C** is to be completed only by those who have stopped working or who are on sick leave.

Please be as frank and honest as possible. Do not dwell too long on any one question as it is your initial thoughts and feelings that are most valuable. Please return your completed questionnaire to us in the prepaid envelope provided by (insert date).

What happens after I have returned my questionnaire?

The questionnaires will come back to the principal investigator (Manpreet Bains) at the University. No one will see your questionnaire. The questionnaire is anonymous, therefore, no individual can be identified.

Any questions?

Please feel free to contact Manpreet Bains, the principal investigator at the University on (01509) 228 152, or M.Bains@lboro.ac.uk

Should the questionnaire raise any health issues which you would like to discuss with someone, you should contact your clinician, nurse or Cancerbackup (0808 800 1234).

Thank you for your time and help!
Section A is to be completed by all participants

1. Below are a series of statements regarding fatigue. By fatigue we mean a sense of tiredness or lack of energy.

Please read each statement and circle a number from 1 to 7 that indicates your degree of agreement with each statement where 1 indicates you *strongly disagree* and 7 indicates you *strongly agree*. Please answer these questions as they apply to the **past 4 weeks**.

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>a)</td>
<td>My motivation is lower when I am fatigued</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>b)</td>
<td>Exercise brings on my fatigue</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>c)</td>
<td>I am easily fatigued</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>d)</td>
<td>Fatigue interferes with my physical functioning</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>e)</td>
<td>Fatigue causes frequent problems for me</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>f)</td>
<td>My fatigue prevents sustained physical functioning</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>g)</td>
<td>Fatigue interferes with carrying out certain duties and responsibilities</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>h)</td>
<td>Fatigue is among my three most disabling symptoms</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>i)</td>
<td>Fatigue interferes with my work, family, or social life</td>
<td>1 2 3 4 5 6 7</td>
</tr>
</tbody>
</table>

2. Below is a list of statements that other people with your illness have said are important.

Please read each statement and circle a number from 0 to 4 that indicates how true each statement has been for you during the past 7 days, where 0 indicates it has been not at all true and 4 indicates it has been very much true.

<table>
<thead>
<tr>
<th></th>
<th>Not at all true</th>
<th>A little bit</th>
<th>Some what</th>
<th>Quite a bit</th>
<th>Very much true</th>
</tr>
</thead>
<tbody>
<tr>
<td>1)</td>
<td>I have a lack of energy</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2)</td>
<td>I have nausea</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3)</td>
<td>Because of my physical condition, I have trouble meeting the needs of my family.</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4)</td>
<td>I have pain</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5)</td>
<td>I am bothered by side effects of treatment</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6)</td>
<td>I feel ill</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7)</td>
<td>I am forced to spend time in bed</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8)</td>
<td>I feel close to my friends</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9)</td>
<td>I get emotional support from my family</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10)</td>
<td>I get support from my friends</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11)</td>
<td>My family has accepted my illness</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
3. We are interested in knowing how you feel. Among the group of four statements in each question please choose one statement that best describes how you have been feeling during the past 4 weeks.

Please circle the number beside your choice.

<table>
<thead>
<tr>
<th>Question</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>12) I am satisfied with family communication about my illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13) I feel close to my partner (or the person who is my main support)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14) Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please tick this box and go the next section</td>
<td>I am satisfied with my sex life</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>15) I feel sad</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16) I am satisfied with how I am coping with my illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17) I am losing hope in the fight against my illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18) I feel nervous</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19) I worry that my condition will get worse</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20) I am able to work (include work at home)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21) My work (include work at home) is fulfilling</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22) I am able to enjoy life</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>23) I have accepted my illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>24) I am sleeping well</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>25) I am enjoying the things I usually do for fun</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>26) I am content with the quality of my life right now</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>i)</td>
<td>0</td>
<td>I don’t feel particularly guilty</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>I feel guilty over many things I have done or should have done</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>I feel quite guilty most of the time</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>I feel guilty all of the time</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| j) | 0 | I am no more irritable than usual |
|    | 1 | I am more irritable than usual |
|    | 2 | I am much more irritable than usual |
|    | 3 | I am irritable all the time |

| k) | 0 | I don’t feel I am being punished |
|    | 1 | I feel I am being punished |
|    | 2 | I expect to be punished |
|    | 3 | I feel I am being punished |

| l) | 0 | I have not lost interest in other people or activities |
|    | 1 | I am less interested in other people or things before |
|    | 2 | I have lost most of my interest in other people |
|    | 3 | It’s hard to get interested in anything |

| o) | 0 | I enjoy |
|    | 1 | I don’t enjoy things as much as I used to |
|    | 2 | I get very little pleasure from the things I used to enjoy |
|    | 3 | I can’t get any pleasure from the things I used to enjoy |

| p) | 0 | I have as much energy as ever |
|    | 1 | I have less energy than I used to have |
|    | 2 | I don’t have enough energy to do very much |
|    | 3 | I don’t have enough energy to do anything |

| q) | 0 | I am no more restless or wound up than usual |
|    | 1 | I feel more restless or wound up than usual |
|    | 2 | I am so restless or agitated it’s hard to stay still |
|    | 3 | I am so restless or agitated I have to keep moving or doing something |

| r) | 0 | I can concentrate as well as ever |
|    | 1 | I can’t concentrate as well as usual |
|    | 2 | It’s hard to keep my mind on anything for very long |
|    | 3 | I find I can’t concentrate on anything |

| s) | 0 | I have not noticed any recent change in my interest in sex |
|    | 1 | I am less interested in sex than I used to be |
|    | 2 | I am much less interested in sex now |
|    | 3 | I have lost interest in sex completely |

| t) | 0 | I have not experienced any changes in my pattern |
|    | 1a | I sleep somewhat more than usual |
|    | 1b | I sleep somewhat less than usual |
|    | 2a | I sleep a lot more than usual |

| u) | 0 | I have not experienced any change in my appetite |
|    | 1a | My appetite is somewhat less than usual |
|    | 1b | My appetite is somewhat greater than usual |
|    | 2a | My appetite is much less than before |
|    | 2b | My appetite is much greater than usual |
|    | 3a | I have no appetite at all |
|    | 3b | I crave food all the time |

| v) | 0 | I made decisions about as well as ever |
|    | 1 | I find it more difficult to make decisions than usual |
|    | 2 | I have much greater difficulty in making decisions than I used to |
|    | 3 | I have trouble in making any decisions |

| w) | 0 | I don’t get more tired than usual |
|    | 1 | I get tired more easily than I used to |
|    | 2 | I am too tired to do a lot of the things I used to do |
|    | 3 | I am too tired to do most of the things I used to do |

| x) | 0 | I enjoy |
|    | 1 | I don’t enjoy things as much as I used to |
|    | 2 | I get very little pleasure from the things I used to enjoy |
|    | 3 | I can’t get any pleasure from the things I used to enjoy |

| y) | 0 | I enjoy |
|    | 1 | I don’t enjoy things as much as I used to |
|    | 2 | I get very little pleasure from the things I used to enjoy |
|    | 3 | I can’t get any pleasure from the things I used to enjoy |

| z) | 0 | I enjoy |
|    | 1 | I don’t enjoy things as much as I used to |
|    | 2 | I get very little pleasure from the things I used to enjoy |
|    | 3 | I can’t get any pleasure from the things I used to enjoy |
4. We would like to know how confident you are in doing certain activities. For each of the following questions, please circle the number that corresponds to your confidence that you can do the tasks regularly at the present time:

<table>
<thead>
<tr>
<th>How confident are you that you can…</th>
<th>Not at all Confident</th>
<th>Totally confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Get information about your cancer from community resources?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>b) Discuss openly with your doctor any personal problems that may be related to your illness?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>c) Do all the things necessary to manage your condition on a regular basis?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>d) Judge how much your illness affects your everyday activity?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>e) Do things other than just taking medication to reduce how much your illness affects your everyday life?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>f) Control aspects of your health condition so as to reduce your need to see a doctor?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>g) Keep the fatigue caused by your illness from interfering with the things you want to do?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>h) Keep the physical discomfort or pain from your illness from interfering with the things you want to do?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>i) Meet your employer's standards for quality of products or services?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>j) Report any other symptoms or health problems you have that they don't interfere with the things you want to do?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>k) Be sure your physical discomfort or pain is reduced?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>l) Control the physical discomfort or pain from your illness from interfering with the things you want to do?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>

5. We would like to know how confident you are in doing certain activities at work today / if you were at work today. For each of the following questions, please circle the number that corresponds to your confidence that you can / could do the task at the present time:

<table>
<thead>
<tr>
<th>How confident are you that you can…</th>
<th>Not at all Confident</th>
<th>Totally confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Meet your employer's standards for quality of products or services?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>b) Report to your supervisor ways to change your work to reduce discomfort?</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>Appendix 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<p>| | | | | | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>c)</td>
<td>Fulfil all of your duties and responsibilities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>d)</td>
<td>the type of work activities you do to reduce discomfort?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>e)</td>
<td>Explain any physical limitations you may have to your co-workers?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>f)</td>
<td>Expectations for job performance?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>g)</td>
<td>Perform most of your daily activities at work?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>h)</td>
<td>Workers to help you with activities that might cause discomfort?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>i)</td>
<td>Keep up with the pace at work?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>j)</td>
<td>the way you work to reduce any discomfort?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>k)</td>
<td>Work at your usual pace</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>l)</td>
<td>Emotional support from co-workers (e.g. listening about any problems)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>m)</td>
<td>Avoid activities that are likely to cause discomfort?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>n)</td>
<td>Thinking about any discomfort so you can get work done?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>o)</td>
<td>Meet your production requirements?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>p)</td>
<td>e your physical workload?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>q)</td>
<td>e your mental workload?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>r)</td>
<td>ge any discomfort effectively while at work?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
</tr>
</tbody>
</table>

Interested in your current work ability:

- Physical demands of your work primarily?  
  - Very good
  - Rather good
  - Moderate
  - Rather poor

- Mental demands of your work primarily? 
  - Very good
  - Rather good
  - Moderate
  - Rather poor

your work ability at its best has a value of 10 points. How many points would you give your current work ability? (0 cannot currently work at all to 10 work ability at best).
Thank you for completing Section A

- If you are currently working please complete Section B only.
- If you are not currently working (e.g. have stopped working, taken early retirement or are on sick leave) please complete Section C only.

Section B (Currently working)

Section B is to be completed by those that are currently working

1. Have you told your line manager about your cancer?  2. Have you told your colleagues about your cancer?

Yes ☐  No ☐  Yes ☐  No ☐

3. With reference to the management of your cancer, have any changes been made to your work (e.g. working fewer hours, reduced workload, change in tasks, flexible hours)? Please describe these briefly below.

Thank you for completing Section B

If you have any further thoughts that you feel are important please use the space provided at the end of this questionnaire.

Section C (Currently not working)

Section C is to be completed by those who have stopped working/long-term sick

1. What best describes your current work status?  2. How long have you been out of the workplace?

a) On sick leave ☐  a) Less than 1 week ☐
b) Unemployed ☐  b) 1-2 weeks ☐
c) Retired ☐  c) 3-4 weeks ☐
d) On incapacity benefit ☐  d) More than a month ☐ Please specify how long
3. Why did you decide to stop working?

4. Did you leave with the intention of returning in the future?
   Yes ☐ No ☐

5. If you decide to return to work in the future will you...
   Return to the same job ☐ (Go to Q7)
   Change job ☐ (Go to Q6)
   N/A ☐ (Go to Q7)

6. What would be your reasons for changing job?

7. Have you told your line manager/supervisor about your cancer?
   Yes ☐ No ☐

8. Have you told your colleagues about your cancer?
   Yes ☐ No ☐

9. Since leaving work have you remained in contact with your line manager/supervisor?
   Yes ☐ No ☐

10. Since leaving work have you remained in contact with your colleagues?
    Yes ☐ No ☐

Thank you for completing Section C
If you have any further thoughts that you feel are important please use the space provided overleaf.
Wish to participate in future research?

If you would like to be contacted to take part in any future research e.g. follow-up and/or interviews please complete the details below. Any personal details will be kept confidential.

Your name ________________________________________ Email address ______________________________________

Contact telephone number (day)_____________________ (evening)__________________________

Please indicate most convenient time(s) to contact you _____________________________________

Thank you for taking time to complete this questionnaire.
Why is this research important?
We would like to gain an insight into the employment decisions of colorectal cancer patients. We are interested in your views on your health, your work and your feelings towards managing your health and work effectively.

The purpose of this diary is to find out more about your experiences of managing cancer and work (if you are working). By gathering information on your thoughts and experiences we aim to be in a position to design interventions to help people like you better manage cancer and employment. With this information we can work with organisations and healthcare professionals to ensure that the necessary support and information is given to older working-aged patients.

What do I have to do?
Completion of this confidential diary is entirely voluntary, but we would be grateful for your help with this study because your contribution can make a big difference. The diary overleaf should take approximately 15 minutes to complete. There are three short sections to this diary:

- **Section A** is to be completed by all participants
- **Section B** is to be completed only by those who are currently working
- **Section C** is to be completed only by those who have stopped working or who are on sick leave.

Please be as frank and honest as possible. Do not dwell too long on any one question as it is your initial thoughts and feelings that are most valuable. Please return your completed questionnaire to us in the prepaid envelope provided, by (insert date).

What happens after I have returned my diary?
The diary will come back to the principal investigator (Manpreet Bains) at the University. No one will see your diary entries. The diary is anonymous, therefore, no individual can be identified.
Any questions?
Please feel free to contact Manpreet Bains, the principal investigator at the University on (01509) 228 152, or M.Bains@lboro.ac.uk

Should the diary raise any health issues which you would like to discuss with someone, you should contact your clinician, nurse or Cancerbackup (0808 800 1234).

Thank you for your time and help!

<table>
<thead>
<tr>
<th>Section A is to be completed by all participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Please describe the 3 most important events that you have experienced over the past 4 weeks.</td>
</tr>
<tr>
<td>…………………………………………………………………………………………</td>
</tr>
<tr>
<td>…………………………………………………………………………………………</td>
</tr>
<tr>
<td>…………………………………………………………………………………………</td>
</tr>
<tr>
<td>…………………………………………………………………………………………</td>
</tr>
<tr>
<td>…………………………………………………………………………………………</td>
</tr>
<tr>
<td>…………………………………………………………………………………………</td>
</tr>
<tr>
<td>…………………………………………………………………………………………</td>
</tr>
<tr>
<td>…………………………………………………………………………………………</td>
</tr>
<tr>
<td>…………………………………………………………………………………………</td>
</tr>
<tr>
<td>…………………………………………………………………………………………</td>
</tr>
<tr>
<td>2. How confident are you that you can do all the things necessary to manage your condition on a regular basis? (Please circle number that applies)</td>
</tr>
<tr>
<td>Not at all Confident</td>
</tr>
<tr>
<td>…………………………………………………………………………………………</td>
</tr>
<tr>
<td>…………………………………………………………………………………………</td>
</tr>
<tr>
<td>…………………………………………………………………………………………</td>
</tr>
<tr>
<td>…………………………………………………………………………………………</td>
</tr>
<tr>
<td>…………………………………………………………………………………………</td>
</tr>
<tr>
<td>…………………………………………………………………………………………</td>
</tr>
<tr>
<td>3. During the past 4 weeks please describe how confident you have felt about managing your illness (e.g. symptoms, treatment, diet)?</td>
</tr>
<tr>
<td>…………………………………………………………………………………………</td>
</tr>
<tr>
<td>…………………………………………………………………………………………</td>
</tr>
<tr>
<td>…………………………………………………………………………………………</td>
</tr>
<tr>
<td>…………………………………………………………………………………………</td>
</tr>
<tr>
<td>…………………………………………………………………………………………</td>
</tr>
<tr>
<td>…………………………………………………………………………………………</td>
</tr>
<tr>
<td>Section A is to be completed by all participants</td>
</tr>
</tbody>
</table>
4. What activities have you carried out to help manage your illness over the past 4 weeks, for example, in terms of your diet, treatment, symptoms and so on?

1. How confident are you that you can do all the things necessary to manage your work on a regular basis? (Please circle number that applies)

<table>
<thead>
<tr>
<th>Not at all Confident</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Totally Confident</th>
</tr>
</thead>
</table>

2. During the past 4 weeks please describe how confident you have felt about managing your work (e.g. tasks, hours)?

|                       |                             |                             |                             |                             |                             |                             |                             |                             |                             |                             |                             |
|-----------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|
### Section B is to be completed by those that are currently working

3. What activities have you carried out to help manage your work over the past 4 weeks, for example, in terms of your hours, work tasks and so on? 

4. If you have any further thoughts that you feel are important please use the space provided below.

### Section C is to be completed by those who have stopped working/sick leave

1. Are you thinking about returning to work? Please could you explain your reasons for this?

2. If you have any further thoughts that you feel are important please use the space provided below.
Interview Information sheet

Managing Cancer and Employment

Background

The nature of the patient and health professional relationship during cancer diagnosis and treatment is important. Health professionals provide information to cancer patients on diagnosis, treatment and prognosis. Although the potential effects of treatment are discussed with patients, little is known about the extent to which disease and treatment effects upon work capacity are discussed with working aged patients (Maunsell et al., 1999; Verbeek, 2006). Consequently, there is a need to explore the type and nature of work-related guidance/advice currently provided to patients in the UK by health professionals (consultant specialists, specialist nurses and occupational health physicians/advisors). This will enable common patterns to be seen and identify subsequent improvements.

Research Aim

- To consider the extent to which health professionals provide work-related guidance/advice to individuals affected by cancer.

What is involved?

Your involvement

- Participate in short interview lasting approximately 20 minutes.

Confidentiality and ethical approval

All information given will be kept strictly confidential and will only be accessible to the research team. The project is anonymous. The identification of participants will not be made known. This project has been granted ethical approval by Loughborough University Ethical Advisory Committee. As members of the British Psychological Society we are also bound by its Code of Conduct and Ethical Guidelines for research.

Contact for further information (Principal Investigator)

Miss Manpreet Bains BSc, MSc (PhD student)
Department of Human Sciences,
Loughborough University,
Leicestershire, LE11 3TU
Tel: 01509 223048
E-mail: M.Bains@lboro.ac.uk

This PhD project forms part of wider research collaboration between Dr Fehmidah Munir, Miss Manpreet Bains, Loughborough University and Dr Joanna Yarker, Goldsmiths College, University of London.
**Interview Schedule**

**Introduction:**

We are conducting a series of interviews to explore the extent to which return to work information / guidance is provided to individuals affected by cancer. To gain a broad and varied insight, we are conducting interviews with health professionals (oncologists, specialist nurses, occupational health) and health and safety managers.

**About you**

a) Briefly describe your job role?

b) How much interaction do you have with patients / clients / employees?

c) On average, how many cancer patients do you see each week?

d) How often would you see or have contact with cancer patient / client diagnosed with cancer / employee diagnosed with cancer?

e) When would you see patient / client with cancer / employee with cancer? (e.g. diagnosed, follow-up, upon RTW, as part of sickness absence procedures, ill-health early retirement decisions)

**Current Practice**

a) In the past, if you have had a patient / client / employee diagnosed with cancer and in employment have you discussed, or given any advice on, how cancer may affect their ability to work? (If yes, probe) (If no, ask why, is the patient referred to anyone else/ directed to alternative information?)

b) What type of work-related information do you give the patient / client / employee? (e.g. written, verbal, sign posting to a charity, advice in reports to GPS/employers)

c) When do you tend to give this advice? and, when would be the ideal time?

d) Are there any factors that influence the type of information / advice you give? (type of work / treatment).
e) Are there any common concerns/questions patients/clients/employees have raised with you about managing cancer and work? (If so, probe).

f) When giving advice, or discussing work and cancer, are there any barriers to you giving as clear/comprehensive advice as you would like? Is there any other clinical/employment/other information that would help you provide more targeted advice? How might you access this?

g) Do you ever discuss the patient/employees’ ability to work/employment with others e.g. consultants, occupational health, line management? If so, what/how do you go about this? If not, do you think this would be valuable to the patient/how would/could it work?

Usefulness of information – potential improvements

a) Do you think the level of information about managing cancer and work currently provided to patients/clients/employees is sufficient? (Probe – e.g. how could it be improved)

b) Whose role do you think it is to provide information/guidance/advice about how cancer and its treatment may impact ability to work?

c) When do you think it would be most appropriate to provide this information?

d) What would be the most effective way to deliver information about how cancer can impact ability to work, and offer guidance about managing cancer and work?

e) Would you recommend any strategies that would help patients/clients/employees manage their cancer and work?

f) Do you think there is suitable and sufficient evidence base within your profession for you to draw on to enable you to confidently advise patient/client/employees on work-related issues?

Do you have anything to add that you feel is of importance and has not already been covered?
## CONSENT FORM

**Managing Cancer and Employment**

(Please Tick)

1. Do you understand the background to the study?  
2. Have you had the chance to discuss this study and ask questions about it?  
3. Have you had the satisfactory answers to all your questions?  
4. Have you been given enough information about the study?  
5. Do you understand that you are under no obligation to take part in the study?  
6. Do you understand that you are free to withdraw from the study?  
7. Do you understand that all information that you provide will be treated as STRICTLY CONFIDENTIAL?  
8. Do you understand that any material used in project reports and academic papers will be used anonymously and will not identify you in any way?  
9. Have you had enough time to come to a decision?  
10. Do you agree to take part in this study?  

<table>
<thead>
<tr>
<th>Participant Name:</th>
<th>Date:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant Signature:</td>
<td></td>
</tr>
<tr>
<td>Investigator Signature</td>
<td></td>
</tr>
</tbody>
</table>