



University  
of Glasgow

Browne, Susan (2013) *The experiences of colorectal cancer patients: a longitudinal perspective*. PhD thesis.

<http://theses.gla.ac.uk/4684/>

Copyright and moral rights for this thesis are retained by the author

A copy can be downloaded for personal non-commercial research or study, without prior permission or charge

This thesis cannot be reproduced or quoted extensively from without first obtaining permission in writing from the Author

The content must not be changed in any way or sold commercially in any format or medium without the formal permission of the Author

When referring to this work, full bibliographic details including the author, title, awarding institution and date of the thesis must be given

# **The Experiences of Colorectal Cancer Patients: a Longitudinal Perspective**

**Susan Browne, MA (Hons), MPhil**

Thesis submitted for the degree of Doctor of Philosophy

General Practice and Primary Care

Institute of Health and Wellbeing

College of Medicine, Veterinary and Life Sciences

October 2013

© 2013, Susan Browne

# **Abstract**

## **Background**

Colorectal cancer is the third most common cancer in the UK for both men and women. Survival rates are improving and more than half of those diagnosed will survive for more than five years. The configuration of care for colorectal cancer patients is likely to shift in line with survivorship strategies which favour self care, a personalised approach, a holistic perspective, and a reduction in specialist care.

## **Aim**

The overall aim of the study is to explore the physical, social and psychological impact of colorectal cancer at diagnosis and one year post diagnosis, with a particular focus on the impact of health care professionals on patients' experience.

## **Methods**

In-depth interviews with 24 participants with a new diagnosis of colorectal cancer, and then follow-up interviews with 19 of the 24 twelve months later.

## **Findings**

This physical illness can largely be understood as an experience of uncertainty. Uncertainty as a reaction to colorectal cancer is associated with lower quality of life and the findings here demonstrate that uncertainty proves profoundly unsettling (in spite of efforts to interpret the experience positively). Current health care provision does not reflect this yet there is clear scope for mitigating the experience of uncertainty.

## **Conclusion**

Primary care is well placed to play a central role in the care of colorectal cancer patients and has the capacity to mitigate aspects of uncertainty that characterise the experience.

# Table of Contents

<b>Abstract.....</b>	<b>2</b>
<b>Table of Contents .....</b>	<b>3</b>
<b>List of Tables.....</b>	<b>7</b>
<b>Acknowledgments .....</b>	<b>8</b>
<b>Declaration of authorship .....</b>	<b>9</b>
<b>Definitions.....</b>	<b>10</b>
<b>1 Introduction and background.....</b>	<b>11</b>
<b>1.1 Incidence, mortality and survival.....</b>	<b>11</b>
1.1.1 A note about staging.....	12
<b>1.2 Quality of life.....</b>	<b>12</b>
<b>1.3 Health care .....</b>	<b>13</b>
<b>1.4 Outline of the thesis.....</b>	<b>14</b>
<b>2 Literature review .....</b>	<b>16</b>
<b>2.1 Literature review introduction .....</b>	<b>16</b>
<b>2.2 Methods.....</b>	<b>16</b>
<b>2.3 Qualitative work on the experience of colorectal cancer .....</b>	<b>17</b>
<b>2.4 The physical experience of colorectal cancer.....</b>	<b>23</b>
2.4.1 Symptoms of colorectal cancer and treatment.....	24
2.4.2 Living with a stoma.....	26
<b>2.5 The psychological experience of colorectal cancer .....</b>	<b>27</b>
2.5.1 The shock of diagnosis.....	28
2.5.2 Physical symptoms affect psychological wellbeing .....	30
2.5.3 Making sense of colorectal cancer .....	30
2.5.4 Confronting mortality.....	31
2.5.5 Beyond diagnosis—coping with colorectal cancer.....	33
2.5.6 Uncertainty.....	35
2.5.7 Biographical disruption.....	37
<b>2.6 The social experience of colorectal cancer .....</b>	<b>45</b>
2.6.1 Employment .....	45
2.6.2 Social lives.....	47
2.6.3 Spousal support .....	49
2.6.4 Relationships .....	50
<b>2.7 The experience of health care .....</b>	<b>51</b>
2.7.1 The role of the CNS and family doctor .....	52
2.7.2 Information provision.....	53
<b>2.8 Cancer survivorship – introduction .....</b>	<b>55</b>
2.8.1 The health and wellbeing of cancer survivors.....	55
2.8.2 Unmet needs of cancer survivors.....	57
2.8.3 The current system of care.....	59
2.8.4 The proposed model of care.....	60
2.8.5 The role of primary care .....	63
2.8.6 Cancer care reviews.....	63
<b>2.9 Chapter summary .....</b>	<b>64</b>
<b>3 Aim and Research Questions.....</b>	<b>66</b>
<b>3.1 Aim .....</b>	<b>66</b>

3.2	Research Questions .....	66
<b>4</b>	<b>Methodology .....</b>	<b>67</b>
4.1	Introduction .....	67
4.2	The PICT study .....	67
4.3	Theoretical assumptions .....	68
4.4	The research question .....	70
4.5	Ethical considerations and approval .....	71
4.6	Participant recruitment .....	72
4.7	Sampling .....	73
4.8	The participants .....	74
4.9	Interviews .....	77
4.10	Coding .....	79
4.11	Generation of meaning .....	80
4.12	Chapter summary .....	81
<b>5</b>	<b>Findings .....</b>	<b>82</b>
5.1	Findings introduction .....	82
5.2	<b>The physical experience of colorectal cancer at diagnosis.....</b>	<b>82</b>
5.2.1	Experiencing the symptoms of colorectal cancer.....	82
5.2.2	Experiencing surgery for colorectal cancer .....	84
5.2.3	Recovering from surgery for colorectal cancer .....	85
5.2.4	The experience of chemotherapy.....	88
5.2.5	The experience of a stoma .....	89
5.2.6	General wellbeing at diagnosis.....	90
5.3	<b>The physical experience of colorectal cancer one year after diagnosis .....</b>	<b>91</b>
5.3.1	Experiencing the long term and late effects of colorectal cancer.....	91
5.3.2	General well-being one year after diagnosis.....	96
5.4	<b>The psychological experience of colorectal cancer at diagnosis .....</b>	<b>97</b>
5.4.1	A diagnosis of colorectal cancer .....	97
5.4.2	Making sense of a diagnosis of colorectal cancer .....	102
5.4.3	Coping with investigations and treatment .....	108
5.4.4	Changed identities at diagnosis.....	110
5.4.5	Psychological struggles .....	111
5.4.6	Psychological support.....	113
5.5	<b>The psychological experience of colorectal cancer one year after diagnosis .....</b>	<b>114</b>
5.5.1	Making sense of a colorectal cancer diagnosis one year after diagnosis.....	115
5.5.2	Fear of recurrence .....	121
5.5.3	Changed identities one year after diagnosis .....	125
5.5.4	Psychological struggles one year after diagnosis .....	127
5.6	<b>The social experience of colorectal cancer at diagnosis .....</b>	<b>130</b>
5.6.1	Finances at diagnosis.....	130
5.6.2	Employment at diagnosis .....	134
5.6.3	Domestic work at diagnosis.....	136
5.6.4	Caring for others at diagnosis.....	137
5.6.5	Social Care at diagnosis .....	137
5.6.6	Social lives at diagnosis.....	138
5.6.7	Eating at diagnosis .....	142
5.6.8	Holidays at diagnosis .....	143
5.7	<b>The social experience of colorectal cancer one year after diagnosis.....</b>	<b>146</b>
5.7.1	Finances one year after diagnosis .....	146
5.7.2	Employment one year after diagnosis.....	148
5.7.3	Domestic work one year after diagnosis .....	149
5.7.4	Caring for others one year after diagnosis .....	150
5.7.5	Social lives one year after diagnosis.....	151

5.7.6	Eating one year after diagnosis .....	152
5.7.7	Travel and mobility one year after diagnosis .....	153
5.7.8	Holidays one year after diagnosis.....	154
<b>5.8</b>	<b>Chapter summary .....</b>	<b>156</b>
<b>6</b>	<b>Colorectal cancer patients experience of health care.....</b>	<b>158</b>
<b>6.1</b>	<b>Experiencing primary care at diagnosis .....</b>	<b>158</b>
6.1.1	GPs and diagnosis .....	158
6.1.2	Delay and dissatisfaction .....	160
6.1.3	GP contact on return from hospital.....	161
6.1.4	The role of the GP, post diagnosis .....	163
6.1.5	Interacting with nurses in the community .....	166
6.1.6	Satisfaction with primary care at diagnosis.....	168
<b>6.2</b>	<b>Experiencing secondary care at diagnosis .....</b>	<b>171</b>
6.2.1	Confirmation of diagnosis and treatment plan .....	171
6.2.2	Participants suspecting cancer .....	173
6.2.3	Diagnosis at investigation .....	174
6.2.4	Investigations.....	176
6.2.5	Treatment plan .....	177
6.2.6	The speed of treatment.....	179
6.2.7	The hospital stay.....	181
6.2.8	Pathology results .....	182
6.2.9	Adjuvant treatment.....	183
<b>6.3</b>	<b>The role of secondary care health professionals at diagnosis.....</b>	<b>183</b>
6.3.1	Clinical Nurse Specialists.....	183
6.3.2	Stoma nurses .....	187
6.3.3	Surgeons .....	188
<b>6.4</b>	<b>Communicating with health professionals at diagnosis .....</b>	<b>188</b>
6.4.1	Communication and understanding at diagnosis.....	188
6.4.2	Treatment decisions at diagnosis .....	191
6.4.3	Plans for follow up.....	193
6.4.4	Communication between primary and secondary care at diagnosis .....	195
<b>6.5</b>	<b>A preference for secondary care.....</b>	<b>196</b>
<b>6.6</b>	<b>Experience of health care one year after diagnosis.....</b>	<b>197</b>
6.6.1	Experiencing primary care one year after diagnosis .....	197
6.6.2	Satisfaction with primary care one year after diagnosis.....	199
6.6.3	Follow up one year after diagnosis.....	201
6.6.4	Secondary care health professionals one year after diagnosis .....	203
6.6.5	Communication and understanding one year after diagnosis .....	204
6.6.6	Satisfaction with secondary care one year after diagnosis .....	205
<b>6.7</b>	<b>Chapter summary .....</b>	<b>206</b>
<b>7</b>	<b>Discussion.....</b>	<b>208</b>
<b>7.1</b>	<b>Introduction .....</b>	<b>208</b>
<b>7.2</b>	<b>Methodological critique .....</b>	<b>208</b>
7.2.1	Longitudinal design.....	208
7.2.2	Reflections on the methods.....	209
7.2.3	Reflections on being part of the PICT study .....	210
7.2.4	Researcher Influence .....	211
<b>7.3</b>	<b>Reflections on the aim of the study .....</b>	<b>212</b>
<b>7.4</b>	<b>Describing uncertainty .....</b>	<b>213</b>
<b>7.5</b>	<b>The experience of uncertainty in three phases.....</b>	<b>215</b>
7.5.1	Phase 1 - to diagnosis .....	216
7.5.2	Phase 2 - diagnosis and treatment .....	217
7.5.3	Phase 3 - after treatment .....	220

<b>7.6</b>	<b>Uncertainties in the context of the literature</b> .....	<b>222</b>
7.6.1	Existential uncertainty in the context of the literature.....	222
7.6.2	Biological uncertainty in the context of the literature.....	224
7.6.3	Medical uncertainty in the context of the literature.....	225
7.6.4	Social uncertainty in the context of the literature.....	225
7.6.5	Where uncertainty does not accommodate the findings.....	227
<b>7.7</b>	<b>The utility of biographical disruption and uncertainty as concepts</b> .....	<b>228</b>
7.7.1	The utility of biographical disruption.....	228
7.7.2	The utility of uncertainty.....	229
<b>7.8</b>	<b>Avoidable and unavoidable uncertainty</b> .....	<b>229</b>
<b>7.9</b>	<b>Recommendations</b> .....	<b>230</b>
7.9.1	Knowledge driven support.....	230
7.9.2	Empathy driven support.....	231
7.9.3	Health care systems reducing uncertainty.....	232
7.9.4	Comorbidity.....	233
7.9.5	A central role for primary care.....	233
<b>7.10</b>	<b>Future research</b> .....	<b>234</b>
<b>7.11</b>	<b>Conclusion</b> .....	<b>235</b>
<b>8</b>	<b>Appendices</b> .....	<b>237</b>
8.1	Letter of ethical approval.....	237
8.2	Letter of R&D approval.....	241
8.3	Patient information sheet.....	242
8.4	Participant consent form.....	245
8.5	Topic guide for first interview.....	246
8.6	Topic guide for second interview.....	247
8.7	Publication from thesis.....	248
	<b>References</b> .....	<b>256</b>

## List of Tables

Table 1 Qualitative patient experience literature .....	18
Table 2 Participant characteristics .....	75
Table 3 The participants .....	76



## Acknowledgments

I would like to express my gratitude to the participants in this study who invited me into their homes on multiple occasions during a difficult period in their lives and to the clinical nurse specialists who helped with recruitment.

Professor Una Macleod, now at Hull York Medical School, has been a stimulating and diligent supervisor whose assistance has not been limited to her academic contribution. I am happy to have this opportunity to thank her for her patient perseverance.

While pursuing this project I have been helped by a large number of people in General Practice and Primary Care at the Institute of Health and Wellbeing, University of Glasgow. Professor Graham Watt agreed to fund this study and also provided invaluable supervisory support by reading drafts and providing useful comments, for which I am very grateful. Professor Frances Mair and Professor Kate O'Donnell have given me the time, space and encouragement to complete this work. Al Dowie gave valuable advice about conducting qualitative fieldwork and about writing a thesis. Catherine McNeil transcribed the interviews and Michelle McKelvie provided administrative assistance. My office roommates and neighbours, past and present, Ying Ying Wang, Eileen Duff, Fiona Turner, Fiona Smith, Rosaleen O'Brien, Anna Matthews, Nicola Burns and Barbara Nicholl, have been invariably encouraging. My colleague and friend Sara Macdonald has listened to numerous thesis related musings and given me greatly appreciated advice and encouragement.

Sue Ziebland from The University of Oxford read transcripts early on and provided insightful comments.

I am grateful to many other people who have helped and encouraged me over the past few years.

Trevor Chisman was at first too much of a distraction and later my greatest ally in this (and all) endeavours. Anna Browne was the inspiration to embark on a career in research a long time ago (although she cannot have known it). More recently she has been patient and gracious while neglected. Without Saul Browne this work would have been finished two years earlier (but the diversion has been a joy).

I would like to thank my friends and family for their encouragement and welcome distractions. In particular, Fiona Mitchell has provided an ear to thesis and non thesis related ponderings for the duration of the project and always provided thoughtful insight. She also provided childcare to allow me to finish. Simon Browne offered to proofread the entire thesis when he had been asked to proofread one chapter.

Finally I would like to thank my parents, who were always very clear about the value of education, for their unwavering (if understated) support. This thesis is dedicated to them.

## Declaration of authorship

All of the work reported in this thesis was designed, conducted, analysed and written up by the author.

The following publication has been prepared from material contained in this thesis:

Browne, S., Dowie, A., Mitchell, L., Wyke, S., Ziebland, S., Campbell, N., & Macleod, U. (2011). Patients' needs following colorectal cancer diagnosis: where does primary care fit in?. *British Journal of General Practice*, 61(592), 692-699.

The following presentations have been made based on material contained in this thesis:

Browne S, Macleod U, Ziebland S: A constant companion: people's experience of uncertainty after a cancer diagnosis - Society for Academic Primary Care, Glasgow, October 2012 - oral presentation

Browne S, Campbell NC, Mitchell E, Wyke S, Ziebland S, Macleod U. Patients' experience of colorectal cancer - the role of primary care. Annual Scientific Meeting of the Society for Academic Primary Care: St Andrews, July 2009 - poster presentation

Browne S, Dowie A, Macleod U, Mitchell E, Campbell N. The Patient Experience of Colorectal Cancer - Implications for Primary Care. 4th National Cancer Research Institute Cancer Conference, Birmingham, 2008 - poster presentation

Browne S, Dowie A, Macleod U, Mitchell E, Campbell N. The Patient Experience of Colorectal Cancer - Implications for Primary Care. 36th North American Primary Care Research Group Annual Meeting, Puerto Rico, 2008 - poster presentation

## Definitions

The following abbreviations are used throughout the thesis:

CRUK	Cancer Research UK
CNS	Clinical Nurse Specialist
GP	General Practitioner
NCSI	National Cancer Survivorship Initiative for England
MRI	Magnetic resonance imaging (scan)
CT	Computerised tomography (scan)
IV	Intravenous therapy
PICT	a Cancer Research UK study entitled Establishing the Potential for Primary Care to Tackle Social Inequalities in Established Colorectal Cancer
QOF	Quality and Outcomes Framework
SIMD	Scottish Index of Multiple Deprivation

# 1 Introduction and background

This chapter provides the context and rationale for this thesis. Colorectal cancer is common and survival rates are improving but the illness and treatment involve a range of physical and psychosocial difficulties that impair quality of life. Primary care is well placed to support colorectal cancer patients but there is little research about the long term support of colorectal cancer patients in primary care.

## 1.1 Incidence, mortality and survival

Colorectal cancer is common. While colorectal cancer mortality rates have been decreasing in the UK since the early 70s as a result of earlier detection and better treatment, it remains the third most common cancer in both males (after lung and prostate) and females (after breast and lung) and the second most common cause of cancer death overall<sup>1</sup>. In 2010, 40,695 people in the UK<sup>2</sup> (3,967 in Scotland<sup>3</sup>) were diagnosed with colorectal cancer. In that year, 15,708 people in the UK died from colorectal cancer<sup>4</sup>. In Scotland, 1,526 deaths were recorded in 2011<sup>5</sup>.

Survival rates are increasing and around half of those diagnosed will live for five years or more. In 2005-2009, around 55% of adult colorectal cancer patients in England survived their cancer for five or more years<sup>6</sup>. In Scotland, for patients diagnosed between 2003 and 2007 one year relative survival rates are 75.7% for males and 73.4% for females and five year relative survival for patients diagnosed between 2003 and 2007 are 55.1% for males and 55.0% for females<sup>7</sup>. If diagnosed at the earliest stage the chance of five year survival increases to 93%.

---

1 <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/bowel/mortality/uk-bowel-cancer-mortality-statistics>

2 <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/colorectal/>

3 <http://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/Colorectal/#summary>

4 <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/colorectal/mortality/>

5 <http://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/Colorectal/#summary>

6 <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/bowel/?script=true>

7 <http://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/Colorectal/#summary>

More than half of colorectal cancer cases are linked to lifestyle and environmental factors (Parkin, Boyd and Walker, 2011) which include: diet, obesity, physical activity, alcohol and tobacco, oral contraceptives and other medications, other medical conditions, radiation, and family history<sup>8</sup>.

### **1.1.1 A note about staging**

A staging system, from A to D, is used for colorectal cancer tumours<sup>9</sup>. A Dukes' A tumour is contained in the innermost lining or slightly growing into the muscle layer. A B tumour has grown through the muscle layer but not spread to lymph nodes. C tumours have spread to one or more lymph nodes in the area close to the bowel. D tumours have metastasised to distant organs such as the liver or lung.

## **1.2 Quality of life**

Colorectal cancer patients have an impaired quality of life. Impaired quality of life is associated with a number of issues including: bowel dysfunction; psychological problems; dietary restrictions; restrictions in patients' level of social functioning; and sexual functioning problems (Sprangers, et al., 1993). When patients' capacity to perform day to day tasks is compromised they are forced to rely on family and friends for household responsibilities and this reliance impairs their quality of life (Dunn, et al., 2006; Northouse et al., 1999). Long-term colon cancer survivors report 'problems with low energy, sexual functioning and bowel problems' (Phipps, et al., 2008). Some problems are general to a diagnosis of cancer (e.g. fatigue and psychological distress) and others are site specific and relate to the function of the bowel (e.g. bowel dysfunction) (Sharpe, et al., 2004; Carlson, et al. 2004). Patients find having a stoma difficult to come to terms with (Persson and Hellström, 2002) and it has a negative effect on quality of life (Brown and Randle, 2005; Engel, et al., 2003), however, the extent of the negative effect of a stoma is questioned by Savatta and Temple (2005).

---

<sup>8</sup> <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/colorectal/riskfactors/#sourcej>

<sup>9</sup> <http://www.cancerresearchuk.org/cancer-help/type/bowel-cancer/treatment/dukes-stages-of-bowel-cancer>

Cancer patients experience a range of social difficulties including: 'difficulties with domestic chores, financial problems, difficulties at work and participating in social activities, and problems with relationships and isolation' (Wright, et al., 2002). Although colorectal cancer patients face difficulties at work they are largely successful in returning to work and sustaining employment (Sanchez, Richardson, and Mason, 2004).

A diagnosis of colorectal cancer affects those around the patient emotionally and Hall, et al., (2012) find that patients are providing emotional support to friends and family who are distressed by their diagnosis.

Gray, et al. (2011) point out that most of the physical, psychological and social factors that predict reduced quality of life are modifiable.

More than three quarters of patients have cancer in addition to other comorbidities (Barnett, et al. 2012). As well as affecting quality of life, physical and psychological comorbidity may have a negative effect on survival (Spiegel, and Giese-Davis, 2003; Macleod, et al., 2000).

### **1.3 Health care**

Treatment for colorectal cancer is usually surgery with or without adjuvant treatment (Scottish Intercollegiate Guideline Network, 2003). Current national guidelines for colorectal cancer recommend that all newly diagnosed patients should have access to a clinical nurse specialist from the point of diagnosis (National Institute for Health and Clinical Excellence, 2004; Scottish Intercollegiate Guideline Network, 2003). Clinical Nurse Specialists (CNSs) are responsible for the coordination of care between healthcare settings, the provision of advice and information, and psychosocial support for patients and their families (Daly and Carnwell, 2003; National Cancer Action Team, 2010).

Patients are usually enrolled in hospital-based follow up but there is a lack of consensus among surgeons regarding what constitutes optimum follow-up; 'surveillance strategies range from a single postoperative visit to lifelong surveillance' (McArdle, 2000). Given the lack of evidence regarding specialist based follow up for colorectal cancer patients, and the existing expertise of

primary care, follow up care provided by primary care may be an alternative acceptable to patients (Rozmovits, Rose and Ziebland, 2004).

Primary care is well placed to provide care for colorectal cancer patients: GPs have specific expertise in facilitating access to high-quality specialist cancer care, experience in management of comorbidities, and experience in providing psychosocial care (Earle and Neville, 2004; Campbell, MacLeod, U and Weller, 2002; Pascoe, et al., 2004). Although primary care is well equipped to support patients with psychological problems, cancer patients tend not to seek help for the psychological problems that arise as a result of their cancer. In one study more than a third of cancer patients met criteria for general distress in the clinical range and almost half of these had not consulted, or planned to consult, with a health professional regarding their distress (Carlson, et al., 2004). Another study estimated the prevalence of major depressive disorder at approximately 8% and found that only half had discussed their low mood with their GP and only one-third had been prescribed any antidepressant medication (Sharpe, et al., 2004).

Improving the patient experience and support for cancer survivors are priorities (Department of Health, 2011) and it is likely that these aims will be achieved with a focus on personalised care planning, self-management, and tailored support (Nekhlyudov, 2009). However, there is little research about the care of long-term cancer survivors in primary care (and what evidence there is suggests that preventative and chronic care is better for long-term breast cancer survivors and controls than long-term colorectal cancer survivors (Khan, et al., 2008)). There is, therefore, a need to understand how patients understand and experience the health care they receive, particularly input from primary care, after a diagnosis of colorectal cancer.

## **1.4 Outline of the thesis**

This thesis comprises seven chapters and begins by reviewing literature relevant to the thesis (chapter two). The literature review has two aims. Firstly, to explore current understanding of the patient experience of colorectal cancer by drawing on a body of qualitative literature, and secondly, to understand the

survivorship debate to date, including the needs of cancer survivors and the current and potential contribution of primary care.

Chapter three outlines the aim of the research and lists the research questions.

Chapter four describes and defends the methods used in this qualitative study. It includes a description of a Cancer Research UK (CRUK) funded study for which the interviews were carried out. The theoretical assumptions underpinning the inquiry and the utility of particular tools are considered. The research process is described including sampling, recruitment and interviews, and the thematic analysis methods are explained.

The findings are presented in chapters five and six. Chapter five examines participants' descriptions of the physical, psychological and social experience of colorectal cancer at diagnosis and one year later. Chapter six focuses on participants' experience of health care at diagnosis and at one year after diagnosis. The contribution of primary and secondary care are considered with a particular emphasis on communicating with health professionals.

Chapter seven begins by reflecting on the study methods and by considering the strength of evidence which this work can claim. The main body of the first part of the discussion is a synthesis of the findings, using uncertainty as the organising concept. The literature is then discussed in relation to the synthesis. Chapter seven concludes with recommendations and practice implications.



## **2 Literature review**

### **2.1 Literature review introduction**

In this chapter, literature relevant to the thesis is reviewed. The literature review has two main aims. Firstly, it aims to explore thoroughly current understanding of the patient experience of colorectal cancer. Secondly, it aims to provide a wider context for this thesis by outlining the literature on cancer survivorship.

An understanding of the patient experience is drawn from the qualitative literature on the experience of colorectal cancer. It is presented in four sections: the physical experience; the psychological experience; the social experience and the experience of health care.

The literature on survivorship is reviewed with the aims of, firstly, understanding the survivorship debate to date, including understanding the needs of cancer survivors and, secondly, focusing on the current and potential contribution of primary care.

### **2.2 Methods**

The section on patient experience is based on a literature search carried out using MEDLINE, CINAHL and Web of Knowledge. The terms colorectal cancer\*, patient\*, experience\* and qualitative\* were used. In addition, further references were identified with citation searches of key authors and the reference lists of included papers.

In 2011 the British Journal of Cancer published a supplement on Cancer Survivorship. The papers in this supplement provided a starting point for understanding cancer survivorship in a current UK context. The terms colorectal cancer\* and surviv\* provided a basis for additional searching, as did the reference lists of included papers.

Papers published before the year 2000 were not included in this review unless they were considered central to the debates in question.

## **2.3 Qualitative work on the experience of colorectal cancer**

A small core of papers comprise the body of qualitative enquiry into the experience of colorectal cancer. They are from North America, the UK and Sweden. For most of these studies surgery for colorectal cancer was an inclusion criteria, and, even when surgery was not an inclusion criteria, the majority of participants had undergone surgery for colorectal cancer. Overall the male-female split is even and the older age range of participants reflects the greater incidence of colorectal cancer in the older population. The majority of participants in these studies are caucasian (as far as can be determined from the information available).

The papers which are drawn on most heavily later in this chapter are described in Table 1.

Table 1 Qualitative patient experience literature

Author, year	Country	N Participants	Participants included	Age range of participants	Male/Female	N Surgery	Time from treatment to interview	N Interviews	N Stoma	N Caucasian	Focus of study
Little 1998	Australia	10	Patients who had undergone colectomy for colorectal cancer	39-79	5/5	all	3 to 144 months	1	8/10		Colorectal cancer and its treatment
Sahay 2000	Canada	20	Patients who had colorectal cancer	48-87		all	At least 6 months post diagnosis (to 7 years)	1	11/20	17/20	The psychosocial impact of colorectal cancer.
Rozmovits 2004	UK	39	Patients who had colorectal cancer	Age 28-68 at diagnosis	20/19		Ranging from very recent to years	1	22/39		Colorectal cancer and its treatment

				33-87 at interview							
Houldin 2006	US	14	Patients recently diagnosed with advanced colorectal cancer	27-67	9/5	all	Three months after diagnosis	1	1	12 Caucasian  1 Asian  1 African- American	Newly diagnosed with advanced cancer.
Simpson 2006	UK	8	Patients who had surgery for colorectal cancer	51-85		all	9-94 weeks	1	3/8		Completing treatment for colorectal cancer.
Desnoo 2006	UK	7	Patients who had stoma reversal at least 6 months before start of	60-78	2/5	all	7 – 20 months from stoma reversal to	1	7/7		Anterior resection syndrome.

			study				interview				
Moene 2006	Sweden	28	Colorectal surgery scheduled. Half with/half without cancer diagnosis	20-86	14/14	all	One week before surgery	1	0		Existential situation before surgery
Houldin 2007	US	14	Caregivers of patients recently diagnosed with advanced colorectal cancer	26-64	4/10	all	Three months after diagnosis	1		12 Caucasian/ 1 Asian/1 African-American	Caregivers of patients newly diagnosed with advanced cancer
Worster 2008	UK	20	Patients undergoing surgery for colorectal	50-82	10/10	all	Four weeks after discharge from surgery	1	0	20/20	The preoperative experiences

			cancer								
Emslie 2009	UK	33	Patients who had colorectal cancer	29-76	17/16		Ranging from very recent to years	1			Gender and spousal support within the experience of colorectal cancer and its treatment
Worster 2009	UK	20	Patients undergoing surgery for colorectal cancer	50-82	10/10	all	Four weeks after discharge from surgery	1	0	20/20	The postoperative experiences.
Hubbard 2010	UK	18	People with colorectal cancer	31-85	15/3	16/18	First interview around time of diagnosis	3			Experiences within the first year following

											diagnosis.
Beech 2012	UK	12	Patients who had received surgery for colorectal cancer	50-87	5/7	all	First interview 2 weeks post surgery	3			The Experience of recovery following surgery from colorectal cancer
Ohlsson-Nevo 2012	Sweden	26	Patients who had surgery for cancer and their partners	Patients 39-86 Partners 40-87	Patients 7/6 Partners 6/7	all	One year after colorectal cancer surgery	1	6/13		The experience of the first year after diagnosis

Together this body of literature comprises 269 participants over 14 studies. Although Little, et al. (1998) falls outside the 2000 to present date range it is included because it is a very heavily cited paper to which some themes that are present in the other papers in this table can be traced. These papers offer an opportunity to examine the experience at various points (their focus ranges from around diagnosis to a year after surgery) from a range of perspectives in time (interviews take place from diagnosis up to twelve years from diagnosis).

This literature is ordered into four main themes covering the patient experience of colorectal cancer: the physical experience; the psychological experience; the social experience and the experience of health care. The literature is presented under these four themes for ease of reading but it should be noted that these themes are inter-related, for example, the physical experience of fatigue is also experienced socially as the patient is unable to work or socialise. A degree of repetition is therefore necessary to impart the numerous ways in which various aspects of the illness impact the patient experience.

## **2.4 The physical experience of colorectal cancer**

In spite of assertions that patients' physical condition has a very significant impact on the life of patients (Ohlsson-Nevo, et al., 2012) it is interesting to note the relative dearth of description of the physical impact of colorectal cancer within the literature on the experience of colorectal cancer. The physical experience receives much less attention than the psychological experience or, indeed, the ability to socialise.

However there is some description of a physical experience and it is an experience beginning with symptoms of the illness but becoming more significant as the physical challenges of treatment arise. In the course of their illness patients may experience bowel dysfunction, fatigue, appetite loss, sleep difficulties, loss of body weight, loss of strength and stamina, bruising and abdominal scars, sexual problems and other treatment side effects (Sahay, Gray and Fitch, 2000; Taylor 2001; Houldin and Lewis, 2006; Desnoo and Faithfull, 2006). Some of these symptoms may become permanent. The physical impact of the illness is most acute for stoma patients who additionally experience a range of issues related to their stoma including sexual difficulties. (A stoma is an



opening from the colon or small intestine to the outside of the body. Stoma bags are used to collect waste at the site of the stoma.) This section looks at the descriptions of symptoms of both the illness and treatment and notes the particular situation of those who require a stoma.

### **2.4.1 Symptoms of colorectal cancer and treatment**

Much of the patient experience literature focuses on the experience post diagnosis, but nevertheless, the lack of attention paid to the symptoms suggests that, relative to the impact of treatment, they are mild. Indeed Taylor, Richardson and Cowley (2010) say that their participants express distress that the symptoms of such a serious illness should be so innocuous that they are difficult to detect.

The most commonly mentioned symptoms resulting from treatment or occurring after treatment are bowel dysfunction, fatigue, and sexual problems.

Bowel dysfunction may occur as a consequence of surgery and the range of manifestations of bowel dysfunction as well as the potential for bowel dysfunction to become permanent are noted in a number of studies. Simpson and Whyte (2006) found a number of elimination problems, including constipation and diarrhoea, present soon after colorectal surgery. Simpson and Whyte (2006) are interested in the period following treatment and carry out a small study with eight patients who had surgery for colorectal cancer. Although they are interested in the time following treatment completion Simpson and Whyte's participants have completed treatment between nine and 95 weeks before the interview.

Sahay, Gray and Fitch (2000) also describe the various ways in which bowel dysfunction compromises physical functioning: by increased frequency of bowel movements; flatulence; constipation; and diarrhoea. They add that other physical difficulties may arise due to bowel dysfunction; particularly disrupted sleep as a result of urgency or leakage. Their findings are based on telephone interviews with colorectal cancer patients between six months and seven years post diagnosis.

Bowel dysfunction may persist for a long time after surgery or even permanently. Desnoo and Faithfull's (2006) interviews with individuals one year after surgery portray the enduring effects of surgery. They focus on the experience of recovery after surgical resection of rectal cancer and the syndrome that results from this operation: 'anterior resection syndrome'. Anterior resection syndrome is comprised of a number of manifestations of bowel dysfunction including: frequency; urgency; flatus; fragmentation; and incontinence of faeces. Individuals experience difficulty distinguishing between flatus and solids and require frequent visits to the toilet. Experiences of anterior resection syndrome vary greatly and the strategies to manage it are devised by trial and error, with input from health professionals, and this process takes time. Individuals develop strategies both to reduce the risk of incontinence, for example by taking anti-diarrhoeal medication, and to manage the eventuality of incontinence, for example by wearing pads.

Fatigue is the most commonly reported symptom in Simpson and Whyte's (2006) study and it prevents individuals resuming their social interests. Houldin and Lewis (2006) inspect the language used regarding symptoms and find attempts to temper the impact of symptoms, for example, diarrhoea is 'sort of' painful, however, fatigue, by contrast is 'profound'. Houldin and Lewis' (2006) work is based on interviews with 14 patients three months after diagnosis who have been diagnosed with advanced colorectal cancer (Dukes' stage C or D).

Sexuality may be impacted by colorectal cancer in a number of ways. Functioning, libido and fertility may be compromised by surgery and adjuvant treatment. Rozmovits and Ziebland (2004) provide examples of sex lives compromised by treatment: radiotherapy triggered the menopause in one woman and resulted in burns to the vagina in another woman. Rozmovits and Ziebland (2004) interview 39 colorectal cancer patients at a range of times from treatment (ranging from very recent to years). More than half of their participants have some experience of a stoma and some were receiving palliative care.

Ohlsson-Nevo, et al. (2012) find that after surgery male patients experience erectile dysfunction and female patients experience sex differently, either with less sensitivity or pain. Ohlsson-Nevo, et al. (2012) is interested in the

experience of the first year after diagnosis and elicits patients' accounts from a single interview one year after colorectal cancer surgery. They are also interested in the experience of couples and interview 13 patients and their 13 partners (separately).

Individuals respond to sexual problems in different ways. Some are able to resume their previous sex life and some make changes to their sex lives but others are unable to resume sexual activity. Patients are more likely than partners to express the loss of a sex life as significant (Ohlsson-Nevo, et al., 2012).

Individuals are likely to experience their symptoms in addition to co-existing morbidities and these are perceived to compound the symptoms of colorectal cancer and slow recovery. Simpson and Whyte (2006) give the example of one woman who believed that her two operations had aggravated her pre-existing chronic fatigue. Ageing is another factor impacting physical wellbeing and Sahay, Gray and Fitch (2000) mention that older patients recognise that age slows them down anyway.

#### **2.4.2 Living with a stoma**

Those who require a stoma experience a number of challenges in addition to those already noted: odour, noise, frequency of cleaning, dietary restrictions, stoma irritation, difficulty finding supplies, and limited ability to travel (Sahay, Gray and Fitch, 2000).

The physical presence of a stoma requires psychological adjustment on the part of the individual. Simpson and Whyte (2006) report a range of responses to having a stoma. Interestingly, those with a permanent stoma consider their situation, once they have undergone a period of adjustment, to be no worse than those without a stoma. However, those without a stoma consider the prospect of a stoma unpalatable. Similarly, Sahay's (2000) participants describe a process of accepting a stoma and of learning to manage a stoma: as participants' learning improves the restriction on their lives lessens.

Rozmovits and Ziebland (2004) consider the psychological impact of a stoma on sexuality. Individuals fear rejection because of their stoma, even within the context of established relationships and reassurances from partners. A stoma may have an enduring impact on the sex lives of individuals. Most individuals resume healthy sex lives yet give accounts of trying to conceal their bag from their partners. The experience of one man, who was unable to resume his sex life because he assumed his wife would find the bag repulsive, highlights the potential for a stoma to end a sex life. Weerakoon (2001) separates the impact of a stoma on sexuality to physical and psychological: direct and indirect. The formation of a stoma damages the nerves and blood supply and the presence of a stoma impairs body image and self esteem. Emslie, et al. (2009) observe a potential gender difference whereby men experience a more negative and longer lasting impact from a stoma on their personal relationships than women. Manderson (2005) says that idealised sex is about losing control and those with a stoma are required to control their body in order to manage elimination and that these two agendas clash.

## **2.5 The psychological experience of colorectal cancer**

Much of the qualitative work on the patient experience of colorectal cancer is concerned with the psychological effects of the illness at various stages. The psychological (and social) impact of colorectal cancer can devastate a patient's quality of life (Sahay, Gray and Fitch, 2000).

The period from diagnosis to treatment is defined by high levels of stress, anxiety and fear (Moane, Bergbom and Skott, 2006; Worster and Holmes, 2008). Immediately after surgery the patient's emotional state reflects their physical well being and those who feel well physically also feel well emotionally but this then gives way to anxiety associated with a cancer diagnosis for everyone (Worster and Holmes, 2009). After surgery patients work to keep life as normal as possible (Houldin and Lewis, 2006) and claim to have a positive outlook and find positive change from their experience (Sahay, Gray and Fitch, 2000). However, a year after surgery uncertainty contributes to individuals feeling that their lives are not 'normal' (Ohlsson-Nevo, et al., 2012) because they must live with fear of recurrence (Simpson and Whyte, 2006). Additionally, patients' very sense of themselves may be called into question by the diagnosis and experience

of colorectal cancer (Rozmovits and Ziebland, 2004; Hubbard, Kidd and Kearney, 2010; Little, et al., 1998; Beech, Arber and Faithfull, 2012).

This section examines the initial responses to a colorectal cancer diagnosis and patients' attempts to make sense of the illness including confronting mortality. It then looks at the strategies patients develop to cope with their diagnosis and live with uncertainty as they move beyond the initial shock of diagnosis. Central to this literature is the notion that a diagnosis of colorectal cancer may fundamentally impact a person's identity and the various ways this is suggested is considered.

### **2.5.1 The shock of diagnosis**

Worster and Holmes (2008) carry out an interview study with 20 patients who are interviewed four weeks after discharge from surgery and find that the shock of diagnosis is so significant that even when patients are asked about their post discharge experiences they elect to talk about their experiences from diagnosis. Worster and Holmes, (2008) title the theme concerned with descriptions of reactions to diagnosis 'I couldn't believe it' to capture the reactions to diagnosis which include disbelief, shock and numbness. The experience of others who have cancer impacts on patients' perceptions to make them fearful. In the early stages of the illness patients feel alone, in spite of being around a lot of people, because 'others could not share the horror of their experience'. For caregivers, too, this is a distressing time defined by feelings of helplessness and being angry at the world. Houldin (2007) adds that these feelings are sometimes manifest in symptoms such as anxiety, depression, diminished appetite and poor sleeping. Houldin (2007) looks at the experiences of caregivers and interviews 14 caregivers (twelve spouses and two friends) three months after diagnosis. However, a colorectal cancer diagnosis is not perceived as catastrophic by all, with variations in response to diagnosis being noted (Worster and Holmes 2008).

The likelihood of colorectal cancer proving terminal varies significantly with stage at diagnosis. Those diagnosed at the earliest stage have an over 90% chance of survival at five years and those diagnosed at the most advanced stage

have an under 10% chance of survival at five years<sup>10</sup>. This differential is not reflected in patient experience described in the literature, certainly, no note is made of an early stage diagnosis of colorectal cancer causing less distress than a late stage diagnosis.

However, age, or rather stage of life, does appear to affect the degree of distress caused by the diagnosis. Older participants respond more calmly, taking a philosophical attitude to their diagnosis (Worster and Holmes, 2008) possibly because expectations of ill health increase with age (Hubbard, Kidd and Kearney, 2010). Hubbard, Kidd and Kearney's (2010) longitudinal study examines the experience of the year following diagnosis and is based on a sample of colorectal cancer patients drawn from a larger longitudinal study. Their subsample of 18 participants are interviewed at three points throughout the year following diagnosis.

Diagnosis at a later stage of life is less likely to conflict with the individual's sense of themselves (Hubbard, Kidd and Kearney, 2010) while at the other end of the age spectrum there is the suggestion that younger caregivers experience heightened distress (Houldin 2007).

Factors related to age appear to make a difference to how well people cope with their diagnosis. Work and parenting dilemmas contribute to anxiety. Indeed for Houldin and Lewis (2006) a colorectal cancer diagnosis requires a rethinking of parenting as parents try to ascertain how to discuss the cancer with their children and also make efforts to spend more time with children. Caregivers are also preoccupied with managing the impact of the illness on children, chiefly by attempting to maintain usual routines for children. They also give accounts of wondering what children should be told about their parent's illness and describe a range of strategies including withholding information from children or being forthright with a positive spin (Houldin, 2007). Younger caregivers also worry about managing the impact of the illness on finances, work, and careers (Houldin, 2007).

---

<sup>10</sup> <http://www.cancerresearchuk.org/cancerinfo/cancerstats/types/bowel/survival/#stage>

### **2.5.2 Physical symptoms affect psychological wellbeing**

Ohlsson-Nevo, et al. (2012) assert that the treated body sets the rules. Physical symptoms can impact on psychological wellbeing. Desnoo and Faithfull (2006) describe how anterior resection syndrome, a syndrome comprised of physical symptoms, impacts psychological wellbeing. The unpredictable nature of bowel pattern means individuals live with a fear of loss of control and incontinence. While life with anterior resection syndrome is preferable to life with an ileostomy individuals do not consider themselves 'normal'. To achieve normality they would have to return to 'normal bowel habits', something they must achieve to have 'recovered'. Simpson and Whyte (2006) add that even when the experience of poor bowel control is transient it is distressing and this distress can be magnified in certain social situations, for example, when staying at other people's homes.

Even apparently more innocuous symptoms can impact psychological wellbeing. McCaughan, et al. (2011) claim watery eyes, a side effect of chemotherapy, can have consequences for gender identity. Accounts from male patients reveal a concern that because of their watery eyes they are perceived as emotional, a characteristic which does not fit with notions of masculinity.

### **2.5.3 Making sense of colorectal cancer**

Little, et al. (1998) claim that the taboo attached to the function of the colon is something that the patient has to consider in addition to their cancer diagnosis. The shock, uncertainty, psychological difficulties and physical difficulties all force the patient to consider things which they had not previously considered, specifically their colon and their mortality. These findings are from an interview study with ten patients who had undergone a colectomy for colorectal cancer with a time since colectomy of between three and 144 months. One patient had experienced a recurrence, another was undergoing investigations for a suspected recurrence and eight of the ten had experience of a stoma.

Taylor (2001) also believes isolation experienced by colorectal cancer patients are due to taboos related to the bowel. However, Worster and Holmes (2008) believe that it is seldom evident that colorectal cancer patients have bowel

disease, they simply have cancer. Their isolation is everything to do with having cancer and nothing to do with taboos related to bowel function.

Moane, Bergbom and Skott's (2006) interview study of 28 people undergoing colorectal surgery, some for malignancies and some for non malignant issues, offers the opportunity to unpick the experience in terms of which aspects of the experience relate to cancer and which to bowel disease and surgery. For those with a benign diagnosis surgery offers the prospect of being able to socialise and travel. Conversely, those with a cancer diagnosis speak of the fear of their cancer being terminal. The days leading up to surgery take on different qualities depending on diagnosis. Those waiting for surgery for a benign diagnosis could use time to relax and gather energy. Meanwhile, the days leading up to surgery are marked by uncertainty about the outcome of surgery for those with a cancer diagnosis. Moane, Bergbom and Skott's (2006) study shows that participants' diagnosis, specifically whether it is benign or malign, dictates their experience.

Houldin and Lewis's (2006) understanding of attempts to make sense of a colorectal cancer diagnosis could apply equally to any cancer diagnosis. The patients' attempts to understand a colorectal cancer diagnosis involves a search for reasons (why me?) for the illness; worrying about the implications of the illness for themselves and their families; engaging in 'life reviews', which include considering how previous actions may have lead to this diagnosis; and confronting mortality.

#### **2.5.4 Confronting mortality**

Given the potential for cancer to be terminal, and the general awareness of such potential, consideration of the possibility of death, confronting mortality, is integral to patient experience of making sense of colorectal cancer. Weisman and Worden (1976) find the existential plight in cancer begins with a definitive diagnosis. Hubbard, Kidd and Kearney (2010) say a colorectal cancer diagnosis replaces the assumption of mortality as far off, or as relevant only to others, with an acute awareness of mortality and the possibility of an imminent death.

For Little, et al. (1998), confronting fear of death and dying is part of the experience of colorectal cancer. Colorectal cancer forces the patient to think



about their own mortality, but there is a degree of irony because death was inevitable all along, and yet it is only rendered truly visible by this diagnosis. Delaying and putting off confrontations with death and dying is a feature of modernity arising from advances in health care and increased life expectancy. Before modernity considering mortality may have been a much more normal practice.

Ohlsson-Nevo, et al. (2012) name their theme on this subject 'Life has a shadow of death'. Cancer has the potential to prove fatal and this knowledge gives rise to 'existential' thoughts. Such existential thoughts may be consuming and can overshadow everything: caregivers find that work and normal activities lose their meaning after a cancer diagnosis. Indeed, confronting mortality is so consuming that patients who experience short, smooth recoveries find assimilating a cancer diagnosis difficult.

The 'shadow of death' is an ongoing feature for Ohlsson-Nevo, et al. (2012): even after successful treatment a colorectal cancer diagnosis entails the abiding possibility of recurrence.

Their lives were shadowed by death because they could not receive definitive assurance of a lifetime cure.

Ohlsson-Nevo, et al. point to Shaha and Cox's (2003) concept of the 'omnipotence of cancer', which adds stigma and 'being classified' to fear of mortality in their depiction of the experience. The colorectal cancer patient experiencing 'the omnipotence of cancer' lives with the

... potential of lifelong illness and death, feels stigmatised by the diagnosis and is classified as belonging to an illness group.

Shaha and Cox's (2003) inclusion of stigma in the experience of colorectal cancer suggests the significance of the context in which a colorectal cancer diagnosis occurs: a cultural context where cancer is imbued with meaning and metaphor.

Cultural and social meanings (including cancer metaphors) will affect the colorectal cancer experience (Beech, Arber and Faithfull, 2012). The idea that

cancer metaphors can impact the illness experience was first proposed by Susan Sontag in 'Illness as Metaphor' in 1978. The cancer patient is required to confront their mortality, partly because the name of their illness is used to achieve political aims.

The use of cancer in political discourse encourages fatalism and justifies 'severe' measures - as well as strongly reinforcing the widespread notion that the disease is necessarily fatal. P84

Sontag, from the perspective of a cancer patient, claims that in many ways the metaphor itself is worse than the illness. Sontag's work marks the beginning of an ongoing debate concerning the cultural and social meaning attached to cancer (and other illnesses)—a vast literature which is not the subject of this study. It would, however, be remiss not to recognise that this is an aspect of the context in which a patient experiences their diagnosis.

### **2.5.5 Beyond diagnosis—coping with colorectal cancer**

Once patients are past the initial shock of diagnosis they employ a range of strategies to cope with a colorectal cancer diagnosis.

Maintaining a semblance of their normal lives becomes the focus for patients as they seek to control the aspects of their lives over which they can still hold sway (Houldin and Lewis 2006). Caregivers employ the same strategy in their efforts to cope with their partner (or friend's) diagnosis. Their attempts to keep life as normal as possible involves accepting help from others and actively adjusting strategies in order to find ways to maintain routines. Caregivers' efforts also include: working hard not to cry; working to block out bad outcomes; working to construct a case for a positive outcome; and talking about worries or concerns about the diagnosis with family and friends (Houldin 2007).

Elsewhere, the strategy of discussing worries is rejected by patients who are keen to find ways to support their families and alleviate the pain that the diagnosis would cause and so they decide against telling members of their families for a period of time. However, deciding not to tell others can add to feelings of isolation (Worster and Holmes 2008).

Patients draw on their faith in order to cope and religion is described as making coping easier and as helpful in explaining the illness to children (Houldin 2007).

In a situation where they have diminishing control, patients with advanced colorectal cancer work to maintain a positive attitude, believing that outcomes will be favourable, and infer that such an attitude may impact outcome. Houldin and Lewis (2006) argue that taking on a positive attitude represents a powerful coping strategy.

Maintaining positive illusions, believing that individuals can keep the cancer from worsening or coming back by maintaining a positive attitude, helps patients with cancer gain a sense of mastery and control over their illness situation.

Caregivers also believe maintaining a positive attitude is desirable, for themselves and their family, but they struggle to maintain optimism (Houldin 2007).

As well as believing in a positive outcome in terms of survival, patients seek positive interpretations as they work to understand their experience in a positive light. They look for positive consequences from the illness, such as increased closeness between couples (Houldin and Lewis 2006). Sahay, Gray and Fitch (2008) describe patients' overall assessment of the colorectal cancer experience as being positive, focusing on improved relationships, becoming pain free, feeling safe as a result of monitoring and living a healthier lifestyle. Those who have not experienced recurrence feel surviving overshadows any adjustments they have to make to their lives, for example, managing a stoma. Even those who experience recurrence of colorectal cancer (and feel weak and lacking in drive), give positive interpretations, based on, for example, shifts in priorities in favour of the things that matter.

In addition to coping with their diagnosis, patients experience anxieties and uncertainty regarding their treatment. Those who had not been in hospital before mention fear of the unknown and experience difficulties around effectively imparting what a hospital experience is like (Worster and Holmes 2008). Some feel pressure, from health professionals, to consent to surgery.

Consenting to treatment necessarily involves loss of control, e.g. completely relinquishing control to surgeons in the case of having consented to surgery. Moane, Bergbom and Skott (2006) add that one week prior to surgery participants describe feeling terror to do with both the surgery itself and the outcome of surgery.

### **2.5.6 Uncertainty**

Uncertainty features throughout the experience—from the diagnostic phase when the diagnosis is uncertain to the fear of recurrence which may last a lifetime and may be exacerbated by health care. Patients work to manage their uncertainty which is experienced to differing degrees and may be more acutely felt by woman.

A diagnosis may remove the uncertainty of the diagnostic phase but it also provokes thoughts about survival and death (Worster and Holmes 2008).

The enduring challenge of psychological adjustment, which begins after treatment is complete, is living with the fear of recurrence (Sahay, Gray and Fitch, 2000). Ohlsson-Nevo, et al. (2012) find uncertainty endures beyond treatment and even when patients are able to describe resumption of an otherwise normal life they continue to live with uncertainty for the future. To live with the knowledge that cancer may recur is to live with uncertainty (McCaughan, et al., 2011).

It seems those with colorectal cancer can at once be consumed by the fear of recurrence yet fail to grasp the likelihood of recurrence. Two studies point to this incongruity. Although Houldin and Lewis's (2006) participants had been informed of the advanced stage of their cancer (Dukes' C or D) they seem to fail to grasp the gravity of their diagnosis. The suspicion that they fail to grasp the gravity of their diagnosis is due, firstly, to conversations being focused on symptoms and, secondly, to there being no hint of resignation or preparing for death. Similarly, the patients in Sahay, Gray and Fitch's (2000) study maintain a positive view which the authors surmise is based on the (sometimes false) understanding that colorectal cancer is a curable disease (or, they suggest, due

to blocking of distress which one interview may not have been adequate to reveal).

Health care may heighten feelings of uncertainty. The period of time leading up to clinic appointments is particularly uncertain (Simpson and Whyte, 2006). Beech, Arber and Faithfull (2012) interviewed twelve patients four times (at two weeks, three months, six months, one year post surgery) during the year following surgery for colorectal cancer to examine their recovery and found that interactions with health professionals could result in uncertainty when the recovery of the patient fails to follow the course predicted by health professionals. After treatment uncertainty can be experienced when patients lack the knowledge to know whether concerns warrant investigation (Beech, Arber and Faithfull, 2012).

Patients endeavour to come to terms with the uncertainty of the disease (Houldin and Lewis 2006) as they are determined not to let uncertainty dominate their lives (McCaughan, et al., 2011). Little, et al. (1998) make the point that all of life is uncertain and requires coping strategies but a diagnosis of colorectal cancer raises questions about the disease and treatment which significantly increase levels of uncertainty.

The experience of uncertainty exists on a scale ranging from an absence of uncertainty to complete preoccupation of uncertainty. Women are more likely to occupy the upper end of the scale and men the lower (with an overlap in the middle). However some men may not be as immune to uncertainty as they claim, rather, they may be reluctant to admit to feeling uncertain as such an admission may contravene notions of masculinity (McCaughan, et al., 2011). Heightened uncertainty may be also associated with a lack of social support (Sammarco, 2003).

Uncertainty is most usually understood to have negative consequences, particularly a preoccupation with fear of recurrence, but it is uncertainty about the future that also results in increased sense of the value of time (Ohlsson-Nevo, et al., 2012).

Although the presence of uncertainty is suggested by some authors it is not presented as a defining characteristic of the experience of colorectal cancer and overall there is a paucity of literature of uncertainty and colorectal cancer.

### **2.5.7 Biographical disruption**

By contrast, qualitative enquiry into the patient experience of colorectal cancer includes a wealth of literature on the impact of the illness on identity. This focus on identity is presented in a number of guises: the disruption of adult identity; the dissolution of identity and its replacement with a 'liminal state'; biographical disruption; and the disruption of self. Although there are clear parallels with the notion of uncertainty and the impact of illness on identity (both ideas suggest the illness calls into question what has previously been taken for granted) it is identity which has received the focus of attention within this literature.

Rozmovits and Ziebland (2004) claim adult identity is undermined and Little, et al. (1998) say identity dissolves, giving way to the 'liminal state'. Beech, Arber and Faithfull (2012) take 'the disrupted self' as their starting point for describing the experience of recovery from colorectal cancer. Hubbard, Kidd and Kearney (2010) say that biographical disruption may occur but that it is not the universal experience of colorectal cancer patients. These four papers, all offering descriptions of an assault on identity by colorectal cancer, are considered here.

For Rozmovits and Ziebland (2004) colorectal cancer undermines the fundamentals of adult identity with its impact being far greater than implied by previous descriptions of colorectal cancer as an embarrassing illness. Colorectal cancer has historically been described as embarrassing because diagnosis and treatment involve discussion of bodily functions and invasive tests. While consideration of colorectal cancer as an embarrassing illness may be useful when trying to raise awareness, it is inadequate in describing people's experience of the disease. Dignity, privacy, independence, employability, professionalism, sexuality and the ability to socialise are all compromised by colorectal cancer and they are all facets of adulthood. Therefore, the very basis of adult identity is disturbed.

Rozmovits and Ziebland (2004) explore the construction of adult identity by drawing on three theories: Douglas' (1982, 1985) description of the social body; Elias' (1939) social history of the development of the idea of adulthood; and Lawton's (1998) idea of the 'unbounded' body as socially untenable. While illness is experienced uniquely by the individual, it is experienced in the context of a society which expects control of bodily functions from the individual. Douglas argues bodily control is an expression of social control. The loss of control of bowel function can represent the spoiling of social order and the individuals' place within the social order. Elais (1939) charts a history of the development of a civilised society, within which the civilised individual has control of his body and bodily functions and where such control is a feature of adulthood. Lawton (1998) argues that those who are dying are removed from society, as in the case of the hospice he studied, not because of taboos around dying, but because their bodies have ceased to function in compliance with social norms. Lawton notes that the unacceptability of the 'unbounded' body is specifically modern and western.

Rozmovits and Ziebland find that these requirements of the modern western adult prove difficult to fulfil with a diagnosis of colorectal cancer. The ability to socialise and to work, central to notions of adulthood, are compromised. The experiences of bowel dysfunction and learning to manage a stoma can result in the loss of dignity, privacy and independence, key aspects of adulthood.

Learning to manage a stoma features heavily in Rozmovits and Ziebland's analysis. Although people are often pragmatic and willing to do whatever necessary to survive, life with a stoma is portrayed as daunting. Accounts of getting a stoma are usually described as a low point in the cancer experience. Those who describe adapting to life with a stoma as being easy are not the norm. Many fear mishaps and when these do happen they are distressing and characterised by childlike dependence. Acquiring a stoma thus involves a loss of independence and privacy and this loss is evident from the outset with the need for input from health professionals.

Little, et al. (1998) also link bowel function to the undermining of identity in their work based on interviews with ten patients who have undergone a colectomy for colorectal cancer. The colorectal cancer patient must consider

their bowel function, where previously they were able to ignore it. A colorectal cancer diagnosis means that identity dissolves to bring about disorientation as the patient enters the 'liminal' state. Liminality is a period of transition where normal limits to thought, self-understanding, and behaviour are relaxed and new perspectives emerge. The liminal state is characterised by ambiguity, openness, and indeterminacy.

The idea of liminality is borrowed from social anthropology. In his studies of rites of passage the social anthropologist Van Gennep (1960) used the term 'liminaire' to describe a stage of transition: the initiate has left behind their previous stage and has not yet arrived at their new stage. Having been rendered distinct from others, the initiate occupies a liminal stage before reincorporation into society.

Developing this notion Little, et al. identify three stages in the narratives of colorectal cancer patients. The stages loosely correlate to chronological stages but Little, et al. recognise that the patient will not experience them as neatly defined stages.

The first stage, cancer patientness, involves a confrontation with mortality for all patients. Patients lose control as they surrender to the system. This initial phase ends with the patient regaining control, however, the immediate impact of the cancer diagnosis is followed by the persisting identification as a cancer patient regardless of time since treatment and whether or not there has been a recurrence.

The second phase, of suspended liminality, involves the continuing identification as a cancer patient and the patients' attempts to construct meaning from the cancer experience by means of a narrative. Patients experience an inability to communicate the nature of the cancer experience and become alienated and isolated from social familiars.

Finally, in the third stage the patient experiences a persistent sense of boundedness, evident from an awareness of limits to space, empowerment and available time. Patients are confined to hospitals, medical schedules and often toilets. A loss of empowerment takes place when social and working roles are



diminished. Later on, patients express uncertainty about future available time- and experience-continued limitations to available space when bowel function limits the potential for travel.

Liminality leads to a permanent disruption to identity and will endure for the colorectal cancer patient who remains in a state of liminality until they die.

As bowel function has come to the fore for these patients so, too, has the prospect of death and this recognition of the importance of confronting mortality to a person's identity is shared by Hubbard, Kidd and Kearney (2010) for whom 'death is obviously the ultimate biographical disruption'.

Hubbard, Kidd and Kearney's (2010) work is concerned with whether the notion of biographical disruption is universally applicable to all colorectal cancer patients. They explore whether or not all patients will experience biographical disruption and look for explanations as to why it may not be a universally relevant idea.

Bury's (1982) work on biographical disruption and Charmaz's (1994) work on loss of self underpin Hubbard, Kidd and Kearney's understanding of biographical disruption.

Bury (1982) introduced the concept of biographical disruption in chronic illness to describe the experience and to explain peoples' responses to their illness. He contends that the onset of chronic illness means the patient must consider pain, suffering and death as relevant to them where previously they may have been distant notions, relevant to others. Bury's concept of coping (1991) involves the patient maintaining their identity in spite of the assaults on it by symptoms and their effects. Patients may bracket off their illness and make it separate from themselves in order to maintain their pre-diagnosis sense of self.

Charmaz (1994) finds that chronic illness necessitates a consideration of mortality and that such consideration disrupts identity. Biographical disruption may be most acute in younger patients, or in those whose good health allowed them to ignore their own mortality. The loss of previous lives due to chronic

illness results in the 'loss of self'. For those with acute illnesses this loss is temporary, but chronic conditions cause ongoing loss of self.

Charmaz (1995) maintains that patients may repair their 'loss of self' by working to regain a pre-illness sense of self. This can be done by 'bracketing the illness': by considering it to be the enemy, or by adapting to the illness and establishing a new identity that incorporates the illness. Context is a key feature in Charmaz's (1994) theory and the degree to which the patient can adapt to the illness depends on context. In Charmaz's (1994) own research she found that middle class men can organise their work in ways to accommodate illness and thereby maintain an 'identity goal', in this case paid employment, in a way that working class men doing physical work could not.

Hubbard, Kidd and Kearney (2010) contend that several people in their study experience biographical disruption because of colorectal cancer. Participants' sense of self is challenged when physical appearances and emotional dispositions are altered by illness. People consider themselves different to their pre-illness self and thus experience a disruption to their sense of self.

Cancer engenders physical, emotional and social change to the extent that an individual can become a stranger unto themselves.

Hubbard, Kidd and Kearney (2010) find that one man's inability to perform his work fits with Bury's idea of dislodging of taken for granted assumptions. This man experiences biographical disruption because he cannot continue working in the way that he assumed he would be able to.

Efforts to cope with biographical disruption are for Hubbard, Kidd and Kearney (2010) evidence of biographical disruption. Patients are able to preserve a sense of self and cope with biographical disruption by undertaking biographical work (rethinking pasts and futures). Attempts to 'keep going', maintain independence, return to work, return to driving are attempts to hold on to pre-illness identity and therefore evidence of biographical disruption. Bury (1991) talks about bracketing off as a mechanism for coping with biographical disruption. Hubbard, Kidd and Kearney (2010) give an example of a man who claimed not to think about his illness while in work. Bury (1991) says 'active

denial' is a way of coping with biographical disruption. Hubbard, Kidd and Kearney (2010) consider the positioning of an individual as he resumes paid employment to be in opposition to a 'sick role' and therefore denial of a sick role.

Accepting that they may die necessitates biographical work on the part of the patient. Hubbard, Kidd and Kearney (2010) describe a woman who accepted that she was going to die and ensured the expression of identity after her death by planning her funeral.

Although Hubbard, Kidd and Kearney (2010) find evidence of biographical disruption they do not find it universally present. They find that age, stage of life, and 'a hard life' may prevent biographical disruption. Hubbard, Kidd and Kearney's findings regarding a hard life confirm Williams' (2000) idea that a hard life may lessen the impact of a cancer diagnosis on a person's identity. Hubbard, Kidd and Kearney (2010) note Faircloth, et al., (2004) and Williams' (2000) assertions that those with multiple chronic conditions may not 'experience the onset of another illness as biographically disruptive but rather it is experienced as one event in an ongoing life of events'. In Hubbard, Kidd and Kearney's (2010) own research they find that 'a hard life' (a hard life may be the 'experience of previous serious illness either personally or within the family') may mean that the diagnosis does not challenge the patient's identity. They found patients who they considered not to have threatened identities to have previous experiences of life threatening illnesses and other health problems. (They also found instances of those who had lived hard lives experiencing biographical disruption, so a 'hard life' does not necessarily negate the possibility of biographical disruption.)

Patients' circumstances can therefore affect the degree to which they may be susceptible to biographical disruption but there is also potential for preventing biographical disruption. Bracketing can be a mechanism for coping with biographical disruption but it can also be a mechanism for preventing biographical disruption (Bury, 1991). This use of bracketing has relevance for those for whom a cancer diagnosis represents a brief disruption before resumption of normal lives. By bracketing the illness, declaring its transient nature, a pre-cancer identity is maintained. Continuing pre-cancer lives and

lifestyles indicates bracketing of cancer and reduces its potential to disrupt a sense of self.

Essentially, for Hubbard, Kidd and Kearney (2010), biographical disruption may or may not occur.

Irrespective of whether an individual will experience cancer as acute or chronic or the length of time that they lived with illness, some of them will experience it as biographical disruption.

Therefore the universal applicability of biographical disruption in chronic illness must be questioned. Hubbard, Kidd and Kearney suggest (2010) 'that people with cancer can experience illness as a physical and emotional assault which disrupts their daily lives but without it being an assault on their identity'. It is possible to lose the ability to socialise and not experience a disruption to identity because, as is the case of one man no longer able to play golf, 'he did not relate this change in social activities to identity and thus, it did not appear to threaten his sense of self'. For these people the biographical work they undertake is their usual biographical work and does not involve mechanisms for coping with biographical disruption. It is possible to experience disruption to physical, emotional, social and daily lives as a result of cancer and yet not have cause to question taken for granted assumptions about body, self or social world.

Beech, Arber and Faithfull's (2012) understanding of disrupted identity resultant from a colorectal cancer diagnosis includes many aspects described by other authors. Hubbard, Kidd and Kearney (2010) and Beech, Arber and Faithfull (2012), for example, note the effect of physical symptoms on identity. They, like Little, et al. note the impact of the restrictive nature of a hospital stay on autonomy and therefore identity. They offer some additional insight, however, by flagging up the importance of the cultural meaning of cancer and by focusing on the process of recovery.

Beech, Arber and Faithfull (2012) develop a model, based on a longitudinal interview study with twelve participants, to capture the experience of recovering from colorectal cancer. The model is comprised of three phases:

disrupting the self; repairing the self; and restoring the self. The third phase, restoring the self, is comprised of two components: a sense of wellness and a sense of illness. These two components can exist in duality although one component is likely to dominate at any given time.

The phases of the model mirror the chronological experience of the colorectal cancer patient. In the first phase, disrupting the self, personal identity is threatened because the onset of symptoms has disrupted the physical body and hospital experiences have disrupted a sense of autonomy. Emotional disruption, associated with the personal and cultural meaning of cancer, occurs as part of this phase which endures until the patient leaves hospital.

The previous life, which may have been taken for granted, is now gone and the future is uncertain.

The second phase, repairing the self, begins at discharge and involves engaging in work to restore the physical body in order to reestablish a sense of identity. The patient analyses the impact of their actions on their body, for example diet is monitored for its effect on the bowel, and they adjust their actions in a quest to achieve autonomy.

The capacity of the 'restoring the self' phase to encompass the shifting duality of its opposing components is taken from the 'shifting perspectives model of chronic illness' (Paterson, 2001). This third and enduring phase will be successful if a sense of wellness takes precedence over a sense of illness. Enjoyment of the emotional, spiritual and social aspects of life and an increasing awareness of the physical body together constitute a sense of wellness. Although a full physical recovery is not a requirement of a sense of wellness the individual is required to display 'body confidence' through 'engaging in meaningful activities' and by viewing failure to progress as an opportunity to alter the activity. In order for a sense of wellness to be restored, the patient must modify plans for the future and judge their illness to be in the past.

In contrast, a sense of illness occurs when the individual is preoccupied with illness, possibly because of ongoing symptoms. Symptoms and pain impair emotional and psychosocial health resulting in a continuing sense of illness.

Health care systems contribute to 'a sense of illness' when follow-up regimes serve to remind people of their illness and the possibility of recurrence.

## **2.6 The social experience of colorectal cancer**

The experience of colorectal cancer impacts on various facets of the patient's social world, yet it is this world that offers them support. Employment becomes problematic when physical symptoms prevent the patient carrying out the requirements of their work. Social lives are severely compromised as bowel symptoms and fatigue get in the way of socialising and travel. Meanwhile, the patient is supported by their social network, most notably their spouses or partners. Communication problems and different coping styles can cause tensions within some relationships while in others an improved closeness occurs.

### **2.6.1 Employment**

Colorectal cancer is more likely to occur in the older population and often patients are retired. However, for those who are working, and especially for those who do not experience a straightforward recovery, the impact of their illness on their employment can be far reaching, sometimes resulting in the end of their career. The implications of this can go beyond the financial impact to impair the patient's identity. When it is possible to resume employment this can signify recovery to the individual. The burden of caring also impacts caregivers' ability to carry out their work responsibilities.

Whether or not individuals are able to resume employment is largely related to their physical wellbeing. Ohlsson-Nevo, et al. (2010) mention participants who have to retire from work as their fatigue means they were unable to work. Rozmovits and Ziebland (2004) detail a range of outcomes with regard to employment. Ten of their sample of 39 have resumed their previous employment but these ten have enjoyed unproblematic recoveries and resumed normal eating and bowel function. Some patients opt to retire early after their illness prompts a shift in priorities, or they simply brought forward an imminent retirement. But others give up work reluctantly because they cannot accommodate their bowel dysfunction within a work context. A taxi driver has to give up his work because he is conscious of the odour from his stoma and a

teacher is unable to accommodate her urgency and commit to time in the classroom. The younger people who are unable to continue with their careers feel the loss acutely.

Indeed, Rozmovits and Ziebland (2004) believe these individuals experience the loss of their professional persona as they are unable to meet the expectations of the professional in society—a finding which, they say, echoes the description of loss of empowerment resulting from an inability to work previously proposed by Little, et al. (1998).

Patients expressed their sense of boundedness in time and space, but also in terms of surrender of social and working roles, and as loss of empowerment. Images of confinement in space often expressed the sense of lost power and social role.

Hubbard, Kidd and Kearney (2010) also believe work can be key to some people's identity. Work provides a 'sense of value and meaning in life'. Therefore, when illness prevents the individual from working it threatens the individual's sense of self.

Elsewhere, work takes on a slightly different meaning. Simpson and Whyte (2006) surmise that, in one instance, a return to previous employment is meaningful in that it signifies a return to normality for one woman. She notes another participant's assertion that his return to work is beneficial to his mental wellbeing. Similarly, for Beech, Arber and Faithfull (2012) a return to work may be a key component of recovery. A return to work requires the patient to have 'knowledge and familiarity with his body' in order to know how 'how his body may react when he returns to work'.

Although domestic work does not pose the challenges associated with operating in a work environment, its physical demands are beyond the scope of many as they recover from surgery. Fatigue, in particular, makes carrying out domestic work difficult (Ohlsson-Nevo, et al., 2010). In their secondary analysis of Rozmovits and Ziebland's (2004) data, where they look at a subsample (33 of the original 39) who were either married or cohabiting in order to focus on gender

and spousal support, Emslie, et al. (2009) find traditional gender roles at play with regard to domestic division of labour.

Emslie, et al. (2009) give the example of a woman who makes extensive preparations before going into hospital in order to lessen the domestic burden placed on her husband, and they find women are concerned about the impact of their incapacity on those for whom they have caring responsibilities and on the running of their household. Men, on the other hand, make no mention of the increased domestic workload their wives may shoulder due to their incapacity. Women give accounts of resuming their domestic roles shortly after discharge from hospital.

Caregivers also describe a significant impact on their own work as they struggle to maintain work commitments while attending to their new caring commitments. Examples of issues caregivers face in a work context are taking time off and fielding enquiries about their partner's illness at work (Houldin, 2007). One participant finds his caring responsibilities impact work to the extent that he has to take early retirement because of the burden of caring and driving. This unplanned retirement causes him to feel angry and bitter (Ohlsson-Nevo, et al., 2010).

### **2.6.2 Social lives**

People with colorectal cancer experience restrictions on their capacity to socialise, whether or not they have a stoma (Sprangers, et al., 1995; Bekkers, et al., 1997; DeCosse and Cennerazzo, 1997; Northouse, et al., 1999; Ramsey, et al., 2000). Patients have concerns about losing control over themselves physically (Moane, Bergbom and Skott, 2006) and this is a horrifying prospect in a social situation. Some of the restriction around social activities is associated with a fear of a potential injury or mishap. Simpson and Whyte (2006) give an example of a participant's reluctance to resume her hobby of dancing because she fears she may suffer an injury.

It is the patient's physical state that dictates whether or not they can engage in a social life (Ohlsson-Nevo 2012). Bowel dysfunction and fatigue create difficulties with regard to socialising.



The impact of bowel dysfunction on the social sphere is evident. Individuals lack the confidence, because of the frequency of toilet visits, to engage in social activities (Desnoo and Faithfull, 2006). Houldin and Lewis (2006) find that symptoms are experienced as losses, for example, individuals lose 'control over their bowels, weight, flatus, sexuality and sleep patterns' and that these losses serve to disrupt their normal lives. Simpson and Whyte (2006) list the ways in which physical symptoms following treatment completion restrict normal life: individuals are unable to bathe independently, cook independently or drive their car. However Simpson and Whyte consider these limitations temporary as they observe the eventual resumption of normal pre-treatment activities.

Bowel symptoms can cause distress and embarrassment and so the individual avoids situations which would previously have been enjoyable (Beech, Arber and Faithfull, 2012). Given that socialising is often associated with eating and drinking, altered bowel habits, including reduced bowel control, chronic constipation, or flatus means that people can face issues socialising (Rozmovits and Ziebland, 2004; Desnoo and Faithful, 2006). Eating socially can also pose problems for some due to forced change of diet. Rozmovits and Ziebland (2004) mention a woman who was able to eat only small quantities and felt compelled to explain her limited capacity for food. Some people feel housebound and isolated because their need to be near a toilet means that they feel they cannot leave home (Rozmovits and Ziebland, 2004).

In Beech, Arber and Faithfull's (2012) analysis of recovery from colorectal cancer they note the efforts patients make, through conducting 'detailed and lengthy observations of diet, noting when consumption of certain foods is associated with socially unacceptable behaviours such as passing flatus', in order to be able to resume their social lives. For Beech, Arber and Faithfull (2012) resumption of a social life is a key aspect of recovery.

Elsewhere it is fatigue, 'a devastating tiredness' that means patients are unable to engage in social activities (Ohlsson-Nevo, et al., 2012).

The limitations to social lives endure beyond the immediate illness and treatment period as patients continue to experience issues with physical

functioning (Marijnen, et al., 2005; Ramsey, et al., 2000; Camilleri-Brennan and Steele, 2002).

Those with a stoma face additional restrictions to their social lives and their ability to travel because of the odour, noise, dietary restrictions, and frequency of cleaning associated with a stoma. Learning to have a social life and to be able to travel with a stoma can take years and may involve distressing accidents (Rozmovits and Ziebland, 2004).

The social lives of partners are also restricted because of the patients' reluctance to leave home. Partners can no longer make plans for the future, such as holiday plans, or accept social invitations because of the uncertainty surrounding the patients' treatment and future wellbeing (Houldin 2007). Ohlsson-Nevo, et al (2012) find evidence of partners feeling resentful that they had to choose between staying at home with the patient or engage in social activities.

### **2.6.3 Spousal support**

Participants describe support from partners as crucial to their 'getting through'. Patients consider their spouses play a critical role in emotional and practical support and are aware of the effort that is involved in providing support. However, patients in turn provide support to their spouses so care giving emerges as 'a dynamic reciprocal process' (Emslie, et al., 2009).

Spouses or partners provide support in different ways to patients. The support provided by spouses (and others) may be separated into emotional and practical support. Emotional support includes accompanying the patient to appointments, showing concern, staying positive, providing encouragement and efforts to control emotions and appear strong to protect spouses and preserve normality (Sahay, Gray and Fitch, 2000; Emslie, et al., 2009). This type of support has been called emotional labour (James, 1989), and some authors contend that women are more likely than men to undertake emotional labour. Practical support, considered more likely to be the domain of men, includes driving, bringing fresh clothes and, in some cases, helping with a stoma (Sahay, Gray and Fitch, 2000; Ohlsson-Nevo, et al., 2012).

Emslie, et al. (2009) make the point, in their analysis of spousal support, that separating emotional support (what women do) and practical support (a male domain) is difficult because emotional support can be demonstrated in practical ways. Additionally, they find many similarities in the support men and women provide. Both men and women provide emotional labour, although their style of delivery may differ, with women supporting in a 'strong and dependable' style, and men in a 'upbeat positive style'.

Women were surprised when men were willing to carry out 'gender inappropriate' work like personal care but traditional gendered roles were also evident. Women organise child care, cover for other caring responsibilities, and cover for domestic work. Men talk about sorting out their finances, as is compatible with the masculine role of breadwinner, and 'protect' women from their stomas.

The impact on the partner of the patient's illness and of caring for the patient can be profound. Partners find the needs of the patients on their return home from hospital overwhelming (Ohlsson-Nevo, et al., 2012). Caregivers carry out care giving tasks in addition to their usual tasks and they often take on the patients' usual tasks too. This increased workload combined with an inability to plan can completely disrupt the caregiver's life (Houldin, 2007).

#### **2.6.4 Relationships**

The illness experience gives rise to, or highlights, communication difficulties between couples. Women find that the upbeat and positive style of their spouses creates a barrier to communicating their fears about death (Emslie, et al., 2009). Couples who were interviewed separately give differing accounts of the same experience, for example, a recovery period was described as short and easy by a patient and extended and problematic by the partner (Ohlsson-Nevo, et al., 2012). The illness could be viewed as either private (the patient's illness), or shared (the couple's illness). Where patients were reluctant to include or involve their partner, by attending appointments together or discussing the illness, this leads to resentment (Ohlsson-Nevo, et al., 2012). The decision not to discuss the illness could be intended to lessen the impact of the illness on the partner and family (Houldin, 2007).

Accommodating different information preferences, or different coping styles, with a couple can prove difficult (Ohlsson-Nevo, et al., 2012; Emslie, et al., 2009). Other issues arise for the couple because of the illness. The relationship becomes more businesslike in order to deal with the increased volume of tasks arising from the illness (Houldin, 2007) and a loss of intimacy is felt acutely by patients (Ohlsson-Nevo, et al., 2012).

While some relationships are strained by the experience of the illness others are strengthened (Emslie, et al. 2009). Partners say the threat to the patient's life makes them value the patient or that sharing worries and fears around death makes them closer (Ohlsson-Nevo, et al., 2012).

## **2.7 The experience of health care**

Qualitative literature on the patient experience of colorectal cancer does not offer meaningful insight regarding interactions with health professionals. Some mention is made of the value attributed to specific health professional roles, namely CNSs and family doctors. Information provision and communication also receive some attention.

Simpson and Whyte (2006) are unusual in that they note the importance of healthcare professionals' contribution to the patient experience. The patient experiences multiple interactions with health professionals throughout their experience. On the day of admission, aspects of their treatment plans are explained to them by a number of health professionals: 'a nurse, a surgeon, physiotherapist, colostomy therapist (if necessary) and anaesthetist' (Worster and Holmes, 2008). The majority of interactions focus on disease process and treatment (Beech, Arber and Faithfull, 2012).

Sahay, Gray and Fitch (2000) find patients are satisfied with the healthcare they receive but elsewhere a mixed picture is evident. Interacting with health professionals can either be distressing or comforting (Houldin and Lewis, 2006). Satisfaction is associated with continuity of care: patients appreciate seeing the same staff at admission that they have encountered through the diagnostic process (Beech, Arber and Faithfull, 2012; Worster and Holmes, 2008; Simpson and Whyte, 2006). Reassurance and sensitive communication are also associated

with positive experiences (Simpson and Whyte, 2006). Patients with advanced cancer feel hopeful after consultations where the possibility of benefitting from new medication is raised (Houldin and Lewis, 2006).

Dissatisfaction is associated with poor communication from health professionals (Simpson and Whyte, 2006). A lack of compassion from physicians when imparting upsetting information (Houldin and Lewis, 2006) and a lack of attention to the individual (Beech, Arber and Faithfull, 2012) are specific examples of poor communication contributing to a negative experience. Elsewhere dissatisfaction arises when patients perceive there has been a delay in diagnostic tests (Houldin and Lewis, 2006) or when there is lack of continuity (Simpson and Whyte, 2006).

Patients' preferences vary and aspects of treatment which may please some can cause concern for others. The short interval between diagnosis and treatment is reassuring for most (Sahay, Gray and Fitch, 2000; Worster and Holmes, 2009) but overwhelming for those who need time to adjust (Worster and Holmes, 2009).

Engaging with a treatment plan requires the patient to relinquish control to health professionals for their safety, support (Beech, Arber and Faithfull, 2012) and for pain control (Little, et al., 1998). Consenting to surgery represents completely relinquishing control and requires trust in health professionals (Worster and Holmes, 2008). After surgery patients continue to experience reduced control of their bodies as anaesthesia affects their control of their legs and mobility (Worster and Holmes, 2009).

The hospital environment is not conducive to sleep (Worster and Holmes, 2009) and patients feel restricted by the requirement to be in hospital (Little, et al., 1998). Discharge from hospital is a major milestone and represents a return to autonomy (Little, et al., 1998). The end of treatment heralds a further milestone characterised by relief (Simpson and Whyte, 2006).

### **2.7.1 The role of the CNS and family doctor**

Input from the CNS is highly valued. The CNS is usually present at diagnosis and can continue to reinforce the diagnosis at subsequent consultations. The CNS is

considered a source of information but communication is not reciprocal. Lack of reciprocity notwithstanding, this contact with the CNS results in confidence for patients and their families and those who do not see a CNS feel unsupported and isolated (Worster and Holmes, 2008).

The family doctor's contribution is to provide information (by responding to queries unanswered by the oncology team), manage referrals, maintain the patient's file, and manage pain and post operative complications (Sahay, Gray and Fitch, 2000). The family doctor is considered to lack specialist cancer expertise (Beech, Arber and Faithfull, 2012) but is a key member of the health care team (Sahay, Gray and Fitch, 2000).

### **2.7.2 Information provision**

Patients say they are satisfied with the provision of information, particularly information about prognosis, treatment, treatment side effects and consequences. Having the opportunity to ask questions and obtain clear answers leads to satisfaction. Patients particularly need information after surgery and feel relieved and appreciate a conversation, at that point, with the surgeon (Worster and Holmes, 2009).

Cancer specialists are the primary source of information and supplementary information is obtained from friends, relatives, the internet and support groups (Sahay, Gray and Fitch, 2000).

Information gaps are evident with patients lacking knowledge about diet (Beech, Arber and Faithfull, 2012) and long term management of the disease, postoperative complications and stoma care (Sahay, Gray and Fitch, 2000). Deficits in information can lead to uncertainty, for example, one patient expressed uncertainty about resuming physical exercise (Simpson and Whyte, 2006). (This patient's predicament also highlighted the inconsistency of information provision in that study, which was conducted in one hospital, as the author was aware that other participants were given clear practical advice with precise time frames about resuming driving, work and lifting objects (Simpson and Whyte, 2006)). The lack of appropriate information available to older patients regarding their sexuality is raised by Rozmovits and Ziebland (2004) who

believe that health professionals may be guilty of assuming that sex is less of a feature in older people's relationships. Patients are surprised when investigations prove difficult to endure, thus highlighting the need for better communication about, and preparation for, investigations (Worster and Holmes, 2009). A key theme for Houldin and Lewis (2006) is patients feeling unprepared for aspects of treatment.

Patient preferences for the style of information delivery vary indicating the need for a individualised approach to information provision. Most patients want information but others prefer only very basic information, for example, what is required of them in terms of attending appointments and investigations. Some patients find information reassuring but for others it raises anxiety. Additionally, there is a variance in levels of understanding, and some patients do not understand information they have been given (Worster and Holmes, 2009). Some patients have an incorrect understanding of their disease and believe their prognosis to be better than it actually is (Sahay, Gray and Fitch, 2000). Written information offers the opportunity for patients to re-refer to it after discharge (Simpson and Whyte, 2006).

Patient information needs vary throughout the course of their illness, sometimes in line with the requirement to contribute to treatment decisions (Worster and Holmes, 2009). Treatment decisions are usually regarding chemotherapy and adjusting doses when toxicity is a problem (Sahay, Gray and Fitch, 2000). However, the provision of a choice in the treatment decision making process creates confusion (Simpson and Whyte, 2006).

Patients become increasingly likely to ask more questions over time but ultimately rely on clinicians to make decisions. Factors which can get in way of patients' ability to ask questions are the shock of diagnosis (Sahay, Gray and Fitch, 2000), feeling doctors are 'too busy' for discussion, (Sahay, Gray and Fitch, 2000; Worster and Holmes, 2009), few opportunities to ask questions and absorb information (Beech, Arber and Faithfull, 2012), and the short interval between diagnosis and treatment (Sahay, Gray and Fitch, 2000). Patients find it difficult to understand medical language and to communicate the horror of the experience (Little, et al., 1998).

## **2.8 Cancer survivorship – introduction**

Today there are approximately two million cancer survivors in the UK. Of those, over 1.2 million are living at least five years past a cancer diagnosis. More than 13% of the population aged over 65 are cancer survivors (Maddams, et al., 2009). These numbers will continue to increase as the UK population grows and ages and as survival and detection of cancer improve. The annual rate of increase in the number of cancer survivors is estimated to be around 3%, and it is anticipated that this rate of increase will continue (Maddams, et al., 2009).

These numbers have precipitated a debate in the UK, which has lagged behind a well established equivalent debate in North America, about the long-term health and well-being of people who have completed treatment for cancer with curative intent. Previously the emphasis of cancer care has been on ensuring timely and effective treatment. More recently, an increasing drive to develop an understanding of the health and supportive care needs of cancer survivors and to develop new ways of delivering services to meet their needs has emerged.

The notion of a ‘cancer survivor’ is somewhat contentious. The term originates in North America and while the debate is as relevant to the UK as to North America, the terminology translates less well with some people in the UK preferring the terms ‘living with cancer’ or ‘being with cancer’. That said, research about survivorship is concerned with the period between the end of treatment and the end of life phase (Ganz, 2005). A long-term survivor refers to someone five years or more post diagnosis.

This section looks first at what is known about the health and wellbeing of cancer survivors including issues which are not addressed by current models of care. Then the current system of care is described briefly before the proposed model of care for cancer survivors is set out. Finally, the role of primary care and of cancer care reviews is outlined.

### **2.8.1 The health and wellbeing of cancer survivors**

A large scale survey comparing the self-reported health and well-being of 780 people with a previous cancer diagnosis with 2740 people without a previous



cancer diagnosis or chronic condition and with 1372 people with one or more chronic conditions shows that cancer survivors in the UK are 'significantly more likely to report poor health outcomes than those with no history of cancer or a chronic condition' (Elliot, et al., 2011). The health profile of cancer survivors is similar to those with a serious chronic health condition and both cancer survivors and those with other chronic diseases have significantly poorer health than the control population. Cancer survivors are also more likely to report other poor social and psychological outcomes.

This picture mirrors the US situation where people with a cancer diagnosis are significantly more likely to report poor health and to have other chronic conditions and face limitations in their day to day activities than those without a cancer diagnosis (Hewitt and Rowland, 2002; Hewitt, Rowland and Yancik, 2003).

Cancer survivors potentially face a range of health and well being problems.

They

are at risk for and develop physiologic and psychosocial late and long-term effects of cancer treatment that may lead to premature mortality and morbidity

Aziz and Rowland, 2003.

Physical problems can arise as a result of surgery or as a result of chemo-radiation treatment, some of these problems may persist and are referred to as 'long term effects'. Patients may also experience 'late effects' which might not become manifest until months or years after treatment is complete. Examples of late effects are the development of second cancers or coronary heart disease after radiotherapy.

Cancer survivors also experience, to various degrees and at various points, emotional problems e.g. anxiety and fear of recurrence. Previous work with breast cancer survivors has identified distress as a feature of cancer survivorship (Carter, 1993; Moyer and Salovey, 1999).

Social difficulties include problems relating to friends and family, financial issues and issues regarding returning to work. Those with young children face issues around childcare, particularly around times of ill health or continuing treatment. Cancer survivors are more likely than people without cancer to indicate that their health prevents them from working in their preferred occupation (Elliot, et al., 2011).

Many of the issues faced by cancer survivors are common to cancers across sites and the survivorship literature focuses more on the commonalities across cancer sites.

The constellation of cancer's long-term and late effects varies by cancer type, treatment modality, and individual characteristics, but there are common patterns of symptoms and conditions that must be recognized so that health and wellbeing can be improved.

Hewitt, Greenfield and Stoval, 2005

However some literature does focus on specific issues attached to particular cancers. Colorectal cancer survivors have inferior physical and mental quality of life than people without cancer. The problems faced by colorectal cancer patients are most acute in the first three years following diagnosis but long-term effects of treatment can persist. Long term and late effects of colorectal cancer include: fatigue; sleep difficulty; fear of recurrence; anxiety; depression; negative body image; sensory neuropathy; gastrointestinal problems; bowel dysfunction; urinary incontinence; erectile dysfunction; impact on work and recreation and sexual dysfunction (Denlinger and Barsevick 2009; Khan, et al., 2011; Sisler, et al., 2012).

### **2.8.2 Unmet needs of cancer survivors**

A number of studies describe the unmet needs of cancer survivors at various stages. The discharge process is the focus of a questionnaire survey by Harrison, et al. (2012) to survivors of breast, prostate and colorectal cancer. Discharge from hospital follow-up is deemed as increasingly important because of recommendations to reduce the length of hospital follow-up (Harrison, et al.,

2012). One third of respondents reported that they were not discharged, highlighting the variation in length of follow-up. Respondents' reported discharge status did not tally with their hospital records, indicating that discharge had not been a clearly defined process. Adverse emotions and a lack of time and information were also reported.

Armes, et al., (2009) look at the supportive care needs of patients in the immediate post treatment period using a questionnaire study at end of treatment and then again six months later. This study finds that 30% of people reported five or more moderate or severe unmet needs at the end of treatment and that 60% of these needs have still not been met six months later. The most frequently cited needs are psychological needs and fear of recurrence. A Danish focus group study looking at rehabilitation needs after hospital discharge identifies five key requirements of a rehabilitation plan. Patients express a need for: continuous support after discharge; support for families; psychological support to help manage fear of recurrence; age specific support groups; and support managing social relations—in particular declining support from friends as well as awkwardness and stigma in social situations (Mikkelsen, et al., 2008).

Mikkelsen, et al. (2009) survey cancer survivors 15 months after diagnosis and find that although over half of those surveyed fear a relapse they do not discuss their fear with either primary or secondary care staff. Similarly, social problems and family problems are not raised with health care professionals.

Turner, et al. (2013) focus on the needs of long-term cancer survivors and their partners using a self-administered postal questionnaire to patients who are five to fifteen years post treatment. Hospital parking; information about familial risk; help managing fear of recurrence; and coordination of care are the most commonly cited unmet needs. Patients also state a preference for health care services to be available locally (Turner, et al., 2013). Khan, Evans and Rose (2011) are also interested in the unmet need experienced by those who have survived at least five years following a cancer diagnosis. They use qualitative methods and interview 40 long-term survivors of cancer to explore their experiences. They identify unmet needs for continuity of care and for information about the late effects of treatment and information about accessing psychological counselling.

Adams, et al. (2012) set out to describe the experience of the partners of cancer survivors in dealing with cancer-related issues in the first three years post-diagnosis using semi-structured interviews with 22 partners of cancer survivors. Partners describe a range of unmet needs and concerns regarding their own and their partner's health and wellbeing. Partners endure their own challenges associated with the impact of the diagnosis but their main focus remains caring for their partner with cancer. The information needs of partners and family members are examined in a systematic literature review and a number of unmet information needs are identified (Adams, Boulton and Watson, 2009). Partners and families express greater need for information about supportive care than information about medical issues. Information needs relating to survivorship include: information about the impact on the family; coping information; prognosis and survival information; will/power of attorney; and financial issues.

A gender analysis of information seeking behaviour of men (with prostate and colorectal cancer) and women (with colorectal cancer) finds that men are as keen to access information about their illness as women. This analysis of requests for information made to a national cancer information service, CancerBACUP, also found that similar information is requested most frequently from all patients 'perhaps reflecting common domains of information and support needs' (Boudioni, et al., 2001).

### **2.8.3 The current system of care**

The current system of care beyond treatment is routine hospital follow-up, usually for five years. Follow-up focuses on detection of recurrence, despite the lack of evidence for the efficacy or cost effectiveness of detection of recurrence. Although there is some evidence that intensive follow-up for colorectal cancer is helpful in improving outcomes (Renehan, et al., 2002).

A number of issues with the current system of hospital-based follow-up are identified. Firstly, more immediate effects of illness and treatment such as bowel or urinary incontinence are neglected. Secondly, the increasing numbers of survivors means that outpatient clinics are struggling to cope with demand, and finally, there are problems with communication between primary and secondary care (Jacobs, et al., 2009).

Primary care is responsible for the health care of cancer survivors after completion of follow-up although it is more commonly associated with involvement at diagnosis and again at the end of life. The care offered to patients after hospital-based follow-up care is currently unstructured and reactive and there are reports of patients feeling abandoned at this point (Kendall, et al., 2006).

Recent work on cancer survivors' experience of primary care service use has identified barriers to the use of primary care. Khan, Evans and Rose's (2011) examination of experiences of primary care finds that while primary care is considered accessible, survivors are hesitant to consult with their GP for cancer-specific matters for three reasons. Firstly, they believe GPs lack the expertise to provide cancer-related follow-up care. Secondly, survivors describe concerns around continuity of care within primary care, specifically a reluctance to discuss cancer-related issues with someone who is unaware of their cancer history. Thirdly, cancer survivors also believe that GPs are 'too busy' to deal with their concerns. Khan, Evans and Rose also note that, in spite of unmet needs being evident, participants are keen to assert that their cancer experience is in the past and that they do not require primary care input. Mikkelsen, et al. (2009) find that a lack of contact with a GP after hospital discharge may be related to the patients' good physical and mental condition and to low confidence in the GP. The partners of cancer survivors are unlikely to seek support for cancer-related issues because of concerns about confidentiality and lack of knowledge of family relationships (Adams, et al., 2012).

#### **2.8.4 The proposed model of care**

Work on improving health care services to meet the health and supportive care needs of cancer survivors must meet the challenge of changing the current paradigm with its focus on treatment and cure (Jacobs, et al., 2009). There is consensus that cancer survivors require early intervention for problems following cancer treatment and also for problems that emerge after completion of treatment, including issues that arise years later as a result of treatment (Elliott, et al., 2011).

Proposed new models of survivor care in North America would be comprised of:

prevention of recurrent and new cancers, and other late effects; surveillance for cancer spread, recurrence, or second cancers; assessment of medical and psychosocial late effects; intervention for consequences of cancer and its treatment...and coordination between specialists and primary care providers to ensure that all of the survivor's health needs are met

Jacobs, et al., 2009

These North American directives are mirrored in recent UK policy from the National Cancer Survivorship Initiative for England (NCSI) (Department of Health, 2010).

The NCSI has articulated a vision that current models of hospital-based follow-up should be replaced with care that incorporates five key shifts: a shift in focus in recovering health and well being; a shift towards holistic assessment, information provision, and a personalised approach to care planning based on assessment of individual risks, needs and preferences; a shift from a clinically led approach to follow-up care to supported self-management; a shift to tailored support that enables early recognition of the consequences of treatment and the signs and symptoms of further disease and tailored support for those with advanced disease; and finally, a shift to measuring experience and outcomes for cancer survivors through routine use of patient-reported outcome measures (Hewitt, Greenfield and Stoval, 2005; Jacobs, et al., 2009; Department of Health, 2010)

The notion of self management is at the centre of North American and UK recommendations for survivorship care (Nekhlyudov, 2009; Foster and Fenlon, 2011).

Following primary treatment, many survivors found ways to self-manage problems they were experiencing. This involved personal resources such as being proactive in seeking out information and support, managing symptoms, thoughts and expectations, carefully planning activities, and making connections with others with similar experiences, as well as self-efficacy (confidence) to do these things.

Foster and Fenlon, 2011

In order to be able to self-manage people need access to support from family, friends and health professionals. They also need self confidence. Supportive care for cancer survivors should be able to identify where support and self confidence are lacking in order to foster people's capacity to self manage (Foster and Fenlon, 2011).

Given the similar health profiles of cancer survivors with people with chronic conditions, Elliot points to the usefulness of models of care used in the management of long-term conditions with an emphasis on self-management and rehabilitation may be appropriate for cancer survivors (Elliot, et al., 2011; Department of Health, 2005, 2007, 2009).

For the majority of cancer survivors the picture is quite positive (Turner, et al., 2013) but others live with cancer as a chronic disease involving periods of remission and periods of relapse (Ganz, 2005). It is therefore important to develop ways to identify the needs of the minority who face long-term cancer-related needs (Khan, et al., 2011) whilst allowing the majority to resume normal life (Turner, et al., 2013) Some work has begun to identify groups or issues that may predict unmet need or require attention. Cancer site or time since diagnosis does not affect health status, psychological morbidity or unmet needs (Turner, et al., 2013). High-risk groups may include those patients who are experiencing depression and those with additional comorbid diseases (Hewitt, Rowland and Yancik, 2003; Foster et al, 2009; Elliot, et al., 2011). Those who had had hormone treatment and those who had experienced low moods were most likely to express unmet needs and it is therefore these groups who are most likely to benefit from targeting the application of psychosocial resources (Armes, et al., 2009). A Canadian survey of colorectal cancer patients to evaluate the continuity and quality of follow-up care concluded that specific groups, namely those who were younger or had rectal (rather than colon) cancer require attention (Sisler, et al., 2012).

### **2.8.5 The role of primary care**

Although the role of primary care is not particularly well defined within the NCSI model there are clear implications for primary care, not least because of planned reductions in the period of hospital-based monitoring. Primary care is well placed to provide care for physical, psychological and some of the social aspects of survivorship care (Nekhlyudov, 2009). Primary care is accustomed to signposting to other services, looking after comorbidities, caring for family members and prevention. Primary care is also well practised in providing continuous longitudinal care, an identified unmet need for cancer survivors.

Discharge from hospital should be managed with oncologists and primary care providers working to clarify their roles in survivorship care (Nekhlyudov, 2009; Adams, et al., 2012). A key appointment at the point of discharge, either a final hospital appointment or a review appointment with primary care, would contribute to an optimal discharge process (Harrison, et al., 2012; Adams, et al., 2012). This appointment would offer the opportunity to discuss psychological issues and the possibility of late effects of treatment arising, provide information on recurrence, long term effects of treatment, healthy behaviour and cancer screening (Khan, Evans and Rose, 2011).

Cancer survivors suggest it would be helpful if GPs were to raise their previous cancer in the course of providing care for other conditions. Such an approach would provide opportunities to discuss any cancer-related issues and satisfy the patient that their cancer history was acknowledged (Khan, Evans and Rose, 2011). Partners would also welcome a proactive approach from primary care giving them an opportunity to discuss issues of concern (Adams, et al., 2012).

### **2.8.6 Cancer care reviews**

In the US 'survivorship care plans' or 'personalised care plans' have come to prominence (Jacobs, et al., 2009). The Institute of Medicine in the US recommend that although there is not yet data to support their effectiveness, every cancer patient should have a care plan (Hewitt, Greenfield and Stoval, 2005). Care plans include: a detailed treatment summary; information on what further follow up required; information on signs of recurrence; what screening is



required; what prevention is required; and advice (Jacobs, et al., 2009). These plans are generated in secondary care and shared with primary care and provide information on how to refer back to secondary care (Jacobs, et al., 2009).

In the UK there is scope for 'cancer care reviews' to fulfil the same objectives and follow a similar format as survivorship care plans in the US. Currently primary care receives some incentive, via the Quality and Outcomes Framework (QOF) (BMA, 2004), to conduct cancer care reviews within six months of diagnosis, however, there has not been clear guidance on how and when this review should be conducted and patients are likely to be unaware that they have had a review (Adams, et al., 2011). Cancer care reviews offer an opportunity for patients diagnosed with cancer to discuss issues related to their cancer without any concerns that they are 'bothering' their GP (Adams et al., 2011).

## **2.9 Chapter summary**

This chapter examines two literatures: a body of qualitative work on the experience of colorectal cancer and an evolving discussion about the care of the increasing numbers of people who are surviving cancer. This review is intended to set the context for this study whereby the experiences of colorectal cancer patients are elicited around the time of diagnosis and one year later.

The picture that emerges from the qualitative work is that of an illness that impacts every dimension of the patient's life. The patient's physical health is compromised most during treatment but physical issues persist one year later. A diagnosis of colorectal cancer is shocking and, although the shock subsides one year later, patients live with 'a shadow of death'. Employment and social lives are restricted because of bowel dysfunction. However there are gaps in this literature: the lack of longitudinal studies means that the focus of this literature is largely on the experience around the time of diagnosis and initial treatment, and the role of health professionals in the experience of colorectal cancer is largely ignored.

Examination of the survival literature, which is not cancer site specific, highlights that many survival issues are common across cancers. Cancer survivors

report poorer health and are more limited in their day to day lives than those who have never had a cancer diagnosis.

The survival literature asserts that cancer survivors' care has become a priority and primary care is well placed to play a central role using models similar to those used for people with chronic illness. But in order for these models to be tailored to the needs of colorectal cancer patients an insight into the impact of health professionals on the current experience of colorectal cancer patients is required. Additionally, there is a need to understand survival issues which colorectal cancer patients may experience that may not be common to all cancers.

## **3 Aim and Research Questions**

### **3.1 Aim**

The overall aim of the study is to explore the physical, social and psychological impact of colorectal cancer at diagnosis and one year post diagnosis, with a particular focus on the impact of health care professionals on patients' experience.

### **3.2 Research Questions**

1. How do colorectal cancer patients describe the physical, psychological and social impact of their illness at diagnosis?
2. How do colorectal cancer patients describe the physical, psychological and social impact of their illness one year after diagnosis?
3. What is the survivorship experience of patients one year after diagnosis?
4. How do colorectal cancer patients perceive the role of health professionals and how does this change over the year following diagnosis?

## **4 Methodology**

### **4.1 Introduction**

This chapter describes and defends the methods used in this qualitative study. It begins by describing a large Cancer Research UK (CRUK) funded study for which the interviews were carried out. The choice of research methods used in any study are determined by both the theoretical assumptions associated with the inquiry and the utility of particular tools with regard to the research questions. These aspects of methodological design and their relevance for this work are considered. The ethical considerations for this study are then detailed along with a note of ethical approval obtained. The research process is described including sampling, recruitment and interviews. Finally, the thematic analysis methods used for coding, interpretation and ultimately the generation of meaning from the data is explained.

### **4.2 The PICT study**

This study originated from one part of a larger study, a CRUK study entitled Establishing the Potential for Primary Care to Tackle Social Inequalities in Established Colorectal Cancer (PICT) carried out by the University of Glasgow and the University of Aberdeen, on which the student was employed. The aim of the PICT study was to understand the potential for primary care based interventions to reduce inequalities in quality of life and survival for colorectal cancer patients and to inform the development of interventions. The PICT study was made up of: a data linkage study; a secondary analysis of existing qualitative data; a quantitative survey; an in-depth interview study; a cost benefit analysis; and a discreet choice experiment (Emslie et al, 2009; Browne et al, 2011; Gray et al, 2011; Hall et al, 2012).

This work is based on data collected for the in-depth interview component of the PICT study. The in-depth interview component was linked to the questionnaire study. Participants were recruited for the researcher administered questionnaire survey in both Aberdeen in Glasgow. The in-depth interview study took place only in Glasgow with a sample of the Glasgow participants who had taken part in the questionnaire study.

### 4.3 Theoretical assumptions

The rationale for the choice of methods employed in research is explained, in part, by the epistemological standpoint underpinning the inquiry.

Quantitative and qualitative methods are associated with contrasting epistemological standpoints, positivism and interpretivism.

Quantitative methods' associated epistemology, positivism, assumes knowledge is acquired using scientific methods which are based on natural science. The researcher is independent of the subject being researched yet can get at the 'facts' of the 'real world'. Quantitative research methods are hypothetico-deductive in their approach: hypotheses are formulated and tested using statistical tests in order to verify the generalisation of the observations (Hammersley, 1992, pp. 159-173.). Quantitative research methods are generally useful for addressing questions to explain and predict relationships between variables.

Qualitative methods' associated epistemology, interpretivism (or constructivism), views that knowledge is a matter of interpretation (or is constructed) and believes that the best way to understand any phenomenon is to view it in its context. The researcher is a data collection tool and interprets the data subjectively. (Subjectivity is acknowledged and steps are taken to maintain objectivity as far as possible.) Qualitative research methods use inductive logic in their approach: the research begins with theories or observations and develops the theories and establishes concepts as the research progresses (Guba and Lincoln, 1994, pp. 105-117). Qualitative methods are used to explore the phenomena under study.

Interpretivism encompasses a range of epistemological positions, including phenomenology, ethnography and grounded theory, each with an associated qualitative methodology.

Phenomenology's application to social science is attributed to the work of Schutz (1899 – 1959) who saw a fundamental difference between the subjects of study in the natural sciences and the subjects of study in the social sciences.

Social reality has meaning for humans and is therefore fundamentally different from natural reality (which has no meaning for its component parts). The meaning of social reality for humans is inseparable from human action and so to understand the social world is to understand the world from the perspective of the subject of enquiry (Bryman, 2004, pp.13- 14).

This work would have lent itself to an phenomenological approach, (qualitative work exploring the experience of illness often employs a phenomenological approach), however, phenomenological studies typically involve a smaller number of research subjects than was planned for this study. Additionally phenomenologists are interested in the essence of the shared experience (Moustakas, 1994, p13), and it seems possible that participants with differing ideas about their experience may have been neglected.

Ethnography originated in anthropology and later found favour with social scientists. It sets out to describe human social phenomena, or culture, and its methodologies are characterised by the immersion of the researcher with the social group being studied and with the detailed notes (thick description) gathered.

Ethnography's focus on the study of groups meant that it would have been inappropriate for eliciting the experiences of this dispersed population. Its requirement on the researchers' immersion would have been inappropriate given the poor health and specifically fatigue that these participants were experiencing.

Grounded theory methods emerged from sociologists Glaser and Strauss's analysis of dying in hospitals. As they carried out their analysis they developed the systematic methodological strategies first described in *The Discovery of Grounded Theory* (1967).

These strategies employed a inductive approach: developing theories grounded in data (Charmaz, 2006). An inductive approach assumes no prior knowledge of subject of study. The literature review should be conducted after developing an independent analysis.

Adhering to the requirement for a literature review to follow analysis meant that a pure grounded theory approach was impossible: the application for funding had included a review of relevant literature (in this case the literature on factors impacting colorectal cancer patients' quality of life). The requirement for funding applications to include reviews of relevant literature means that qualitative studies, which are a critical part of health service research and patient experience research, very rarely use true or pure grounded theory.

Rather they borrow from grounded theory, for example, Macdonald et al. (2012) used an analytical approach based on the pragmatist view of grounded theory in their study of general practitioners' use of sickness certification in depression.

Such a pragmatic approach means that in spite of being unable to carry out an entirely inductive analysis researchers can utilise grounded theory's systematic methodological strategies and construct abstract theoretical explanations of social processes.

A modified grounded theory approach was adopted whereby, although some literature was reviewed before fieldwork took place, the methodological strategies for analysis advocated by grounded theory were used as a blueprint from which to borrow. There was adherence to fundamental principles of grounded theory including:

Simultaneous involvement in data collection and analysis is essential, rather than data being first collected and then analysed. Fundamental techniques such as theoretical sampling, theoretical saturation, hierarchical coding processes and identification of a core category should be used by the researchers.

Berterö, (2012)

#### **4.4 The research question**

Some authors consider it is the research question which should primarily guide design. Bryman (2004) argues for a pragmatic approach whereby the appropriateness of the methods to the research question shapes study design.

Methods are appropriate to the research problem, rather than a researcher's epistemological reasoning. A range of research methods should make up the research toolkit, which could be used to answer different research questions (Snape and Spencer, 2003, pp.1-23). Baum (1995) also suggests 'the methods are simply tools that are used to further knowledge' and should be selected on the basis of suitability to the research question.

The aims of this study were to explore the physical, social and psychological impact of colorectal cancer at diagnosis and at one year post diagnosis and to explore the impact of health care professionals on patients' experience. This agenda, to explore the meaning from colorectal cancer patients' own point of view within the context of the health care they were receiving, fits within an interpretivist perspective. Such an exploratory agenda requires qualitative methods in order to generate rich, detailed data that has the power to explain and to account for context and complexity.

#### **4.5 Ethical considerations and approval**

The main ethical issue for this study was the potential for discussions about cancer to prove upsetting for participants. The application for ethical approval made clear that the interviews would be done by an experienced primary care researcher who could provide participants with information on sources of support if they required it.

The application also noted the potential for interviews with patients with cancer may prove draining to the researcher but that the researcher would be supported by the research team.

The inclusion of adults who have a terminal illness in the study was justified by the need to explore the particular needs regarding psychological and social care, care of co-morbidities, and access to specialist cancer care for these patients.

Eligible patients were given an information sheet (Appendix 3) and asked by a member of their clinical team (in Glasgow this was the CNS) for permission to be approached by the student. The student telephoned and explained the purpose of the study as well as what participation would entail and, where appropriate,



arranged a time to visit. Participants were given 24 to 48 hours to consider whether to take part. At the first in-person meeting with each participant the student obtained informed consent (Appendix 4) and administered the questionnaire survey. At this meeting participants indicated their willingness (or not) to take part in an in depth interview.

Participants were given assurances regarding confidentiality and assured that information they provided could not be attributed to them.

This project was reviewed and fully approved by the Multi-Centre Research Ethics Committee for Scotland, Committee A in January 2006 (Appendix 1). Research and Development Management Approval was granted by Greater Glasgow Primary Care Division in March 2006 (Appendix 2).

## **4.6 Participant recruitment**

Participants for the PICT study were eligible for inclusion if they had had a definitive diagnosis of colorectal cancer, and had commenced their initial treatment (normally surgery or, in non-resectable cases, palliative radiotherapy or chemotherapy). Participants were excluded if they were unable to give informed consent or, in the opinion of their clinical team, had a life expectancy of less than one month.

Where surgery was scheduled, patients were recruited after surgery and this included patients scheduled for pre-operative chemotherapy and/or radiotherapy. Where surgery was not planned, for example, patients referred for palliative chemotherapy/radiotherapy or patients with no planned treatment, recruitment occurred during their first course of treatment (chemotherapy or radiotherapy) or at their first follow-up appointment.

Only patients with newly diagnosed disease were recruited. The time at which patients were no longer be considered 'new' was defined as: three months post surgery or, three months from first treatment, if no surgery or, three months from diagnosis if no treatment at all.

## 4.7 Sampling

Qualitative research requires purposeful sampling. Purposeful sampling is 'selecting information-rich cases for study in depth' (Patton, 1990, p169). Subjects are sought if they have experience of the phenomenon being investigated. There is no requirement for generalisability.

The study sought to capture a wide range of experiences so a maximum variation sample was sought (Marshall 1996). This is a purposeful strategy which samples for heterogeneity. Maximum variation sampling allows exploration of how a phenomenon is understood among different people, in different settings. When using a maximum variation sampling method a small number of cases are selected that maximize the diversity relevant to the research.

The sampling strategy was developed in order to capture the differing experiences newly diagnosed colorectal cancer patients and informed by socio demographic and clinical characteristics. In this study it was decided that the relevant factors were: age, sex, socio-economic status and level of co-existing morbidity. The Scottish Government's measure for identifying areas of deprivation within Scotland, The Scottish Index of Multiple Deprivation (SIMD), was used as a measure of socio-economic status<sup>11</sup>. Co-existing morbidity was judged using a part of the PICT questionnaire which had asked participants to list their other illnesses.

Participants were selected to ensure adequate representation of patients across the attributes in the sampling frame. The balance between patients with metastatic and non-metastatic disease was monitored to ensure that sufficient numbers of patients survived to complete the second in-depth interview.

Typically, qualitative studies do not include large numbers of participants (Sandelowski, 1995), and sample size was based on achieving a sufficient number to capture differences in patient experience. Interviews were completed when interviews revealed no new ideas, experiences or insights, the concept referred to in the literature as 'saturation' (Bowen, 2008).

---

<sup>11</sup> <http://www.scotland.gov.uk/Topics/Statistics/SIMD>

## 4.8 The participants

Twenty-four colorectal cancer patients took part in an in-depth interview within three months of diagnosis with colorectal cancer and 19 of these patients were re-interviewed twelve months later.

The sample at first interview was comprised of nine men and 15 women ranging in age from 34 to 84 at the time of diagnosis. (Diagnosis refers to the date of operation if it was available, if it was not available then date of positive biopsy; if that was not available then the date of imaging was used and if that was not available then the date of investigation where diagnosis was made was used.)

The sample included a range of Dukes' stages, 22 of the original 24 had had surgery, one was receiving palliative treatment and one was receiving chemo radiation while he attempted to lose weight in order to become fit for surgery.

19 of these patients were re-interviewed twelve months later. It was not possible to re-interview five of the original 24 participants as two had died, one felt too unwell to be interviewed and two were no longer contactable through the details held.

Table 2 Participant characteristics

<b>CHARACTERISTICS</b>	<b>Participants (n=24)</b>	<b>CHARACTERISTICS</b>	<b>Participants (n=24)</b>
<b>No. of interviews</b>		<b>Sex</b>	
1	5	Female	15
2	19	Male	9
<b>Age at first interview</b>		<b>Education level</b>	
Below 50	5	No formal qualifications	10
50-70	12	O levels/A levels	5
Over 70	7	University/college degree	2
		Other qualifications	7
<b>Employment status</b>		<b>Deprivation quintile</b>	
Employed/self-employed	7	1 (most affluent)	7
Retired	14	2	4
Unemployed	2	3	1
Looks after home	1	4	3
		5 (most deprived)	9
<b>Dukes' stage</b>		<b>Stoma</b>	
A	4	None	19
B	9	Temporary	2
C	7	Permanent	3
D	2		
Missing	2		
<b>Ethnicity</b>		<b>Cancer site</b>	
Caucasian	23	Colon	14
Latin American	1	Rectum	8
		Rectosigmoid	2

Table 3 shows the characteristics of each of the interviewees. Participants, (and anyone else mentioned in the course of interviews) have been assigned pseudonyms as a measure to ensure anonymity. Pseudonyms were generated using Scrivener<sup>12</sup>: a writing programme which has a feature that generates names based on origin.

**Table 3 The participants**

Pseudonym	Male/ Female	Deprivation quintile	Age at first interview	Ethnicity	Education Level	Employment Status	Cancer site	Stoma	Dukes' stage
Geoff	M	5	75	White	No formal qualifications	Retired	Colon	No	C
Berta	F	1	50	Latin American	O Levels/ A levels	Employed	Colon	No	B
Teresa	F	5	70	White	Other qualifications	Retired	Rectum	Temp	A
Meg	F	3	65	White	O Levels/ A levels	Retired	Colon	No	D
Muriel	F	1	68	White	No formal qualifications	Retired	Rectum	No	A
Lorraine	F	1	34	White	O Levels/ A levels	Employed	Rectum	Temp	C
Doris	F	5	84	White	No formal qualifications	Retired	Colon	No	B
Glenda	F	2	67	White	University/ College degree	Retired	Colon	No	C
Jacqueline	F	2	55	White	Other qualifications	Looks after home	Colon	No	B
Alice	F	5	69	White	No formal qualifications	Retired	Rectum	Yes	A
Maisie	F	5	64	White	No formal qualifications	Unemployed	Recto-sigmoid	No	C
Hugh	M	5	48	White	No formal qualifications	Unemployed	Colon	No	B
Charlie	M	5	72	White	No formal qualifications	Retired	Rectum	No	C
Philippa	F	1	64	White	University/ College degree	Retired	Colon	No	A
Scarlett	F	2	72	White	O Levels/ A levels	Retired	Colon	No	missing
Kirsty	F	4	37	White	Other qualifications	Employed	Rectum	Yes	B
Danny	M	1	51	White	O Levels/ A levels	self employed	Colon	No	missing
Harry	M	1	81	White	Other qualifications	Retired	Rectum	No	C
Stephanie	F	1	53	White	Other qualifications	Employed	Colon	No	D
Tracey	F	5	46	White	No formal qualifications	Employed	Colon	No	C
Clive	M	4	59	White	Other qualifications	Retired	Rectum	No	B
Andrew	M	2	55	White	Other qualifications	Employed	Recto-sigmoid	Yes	B
Jason	M	4	76	White	No formal qualifications	Retired	Colon	No	B
Samuel	M	5	81	White	No formal qualifications	Retired	Colon	No	B

<sup>12</sup> <http://www.literatureandlatte.com/index.php>

## 4.9 Interviews

Interviewing is a very popular method of data collection in health research; it is logistically feasible and, relative to observation, not intrusive (Ziebland and McPherson 2006; Starks and Trinidad, 2007).

The interview schedules reflected the aims of the PICT study and included questions on perceptions of the physical, psychological and social impacts of cancer, co-existing morbidities, and treatment and care accessed and received. Rather than a prescribed set of questions the interview topic guides (Appendices 5 and 6) functioned as a checklist to ensure that all areas of interest had been covered. As the fieldwork progressed and familiarity and confidence with the guide improved the paper copy was dispensed with and questions were recalled from memory thereby facilitating more natural conversations which generated richer data.

In light of the poor health of participants at the time of interview (and the potentially sensitive nature of the study) the student made it very clear to respondents that they could stop the interview or withdraw from the study at any time if they wanted.

Interviews were opened by asking participants to talk about 'everything that had happened' after they had been diagnosed. The intention of using the 'tell me the story' approach (Seidman 1998) was that participants would focus on events of greatest importance to them. Participants were asked to give their story from after diagnosis as any potential intervention was likely to intervene after diagnosis. However, participants invariably choose to begin their story either at the point of first noticing or presenting with symptoms or at the diagnostic consultation itself. Having been made cognisant of the importance of reflecting on symptoms and of the diagnostic consultation and wanting to gather data on this, the student altered the opening question to ask simply for 'the story of their cancer'.

The student attempted to allow participants to recount their story in their terms and interrupt only for clarification and then return to ask about the areas covered in the topic guide. This strategy was successful in some cases but often

patients preferred to be asked a series of questions and in those cases the interviews were more structured by detailed questioning from the outset.

In an effort to elicit the areas of concern or importance to participants, which might not have been included in the interview guide, participants were asked if they were happy that everything of importance to them had been covered. To the same end care was taken not to interrupt long pauses or silences as these were frequently followed up by key disclosures, for example, Jacqueline voiced her fears about death and her thoughts about how the different members of her family would cope in the event of her death after a long pause.

Six of the participants had their spouse present for some or all of the time spent interviewing. Although it may have been preferable to interview participants alone (for example, Berta discussed the impact of cancer on her relationship in a way that she is unlikely to have done had her husband been present) the student was clear it would be inappropriate for her to ask that the spouse leave. In three cases spouses contributed to the interview (Geoff, Charlie and Jason) and in three cases the spouse did not contribute (Hugh, Muriel and Alice).

Silverman cautions that interview data merely represent participants' constructs of their own behaviour (Silverman, 2001). Cornwell (1984) labels accounts given at first interviews as 'public' and suggests that 'private' accounts can be obtained at subsequent interviews. The first in-depth interviews for this study were recorded at the second meeting with participants. During the first meeting with participants a researcher administered questionnaire had been completed and participants had often expanded on the 'tick box' answers required by providing context and elaborating on their responses. Additionally, they often volunteered their story at the outset of this first meeting or after the questionnaire had been completed. In the second meeting they were therefore asking them to repeat 'their story' for the tape recorder. It appeared that, rather than gain additional access, as Cornwell suggests, the narratives lost the immediacy of their first telling. The in-depth interviews may have suffered, most notably in the level of detail provided, as a result of being collected after the questionnaire survey.

Initial interviews were carried out during 2006/07. Patients' views and use of services often change as their disease, treatment and follow up progress, so the initial interviews at six to eight weeks after first treatment were followed by further interviews at twelve months. This longitudinal design was intended to incorporate a temporal dimension to the study and ensure sufficient depth of qualitative data. Initial interviews had lasted about an hour but follow up interviews were significantly shorter. The differing lengths reflected the magnitude of participants' experience, a cancer diagnosis and treatment, at the first interview, and, for most, the return to some semblance of normality by the second.

All interviews were audio-taped (with the permission of the participant) and transcribed verbatim.

#### **4.10 Coding**

The transcripts were read and re-read early on in the data collection process by both the student and her supervisor. Reliability of analysis may be achieved by two or more researchers reading and coding the transcripts (Pope, Ziebland and Mays, 2000).

A coding frame was jointly developed from a number of a priori themes based on the research questions, for example, key themes like 'patient experience of care' and 'patient need' were identified prior to analysis (Kelle, 1997). Analysis was on-going throughout fieldwork (Pope, Ziebland and Mays, 2000) and additional themes, such as 'the role of the CNS', were identified and fed back into subsequent interviews. This iterative approach, whereby themes are identified and fed back into the data collection process (Miles and Huberman, 1984) facilitated better understanding of the factors that might impact health and wellbeing after diagnosis. The main themes which emerged from these data relate to the needs patients identified following their diagnosis of colorectal cancer and the professional input accessed by the patients with respect to these needs.

Mays and Pope (2000) claim that the quality of 'qualitative research can be assessed according to two broad criteria: validity and relevance'. During coding



'deviant cases' (those that do not fit emerging theories) were considered in order to facilitate the refinement of theories thus improving validity. Additionally, the student maintained an awareness of the ways in which she and the methods used may have influenced the data collected (reflexivity) in order to ensure validity.

The aim of the coding process was to label related excerpts of data so that they could be retrieved with ease. Data was systematically coded to the coding frame and attention was paid to the volume of data being coded at each code so that the volume of information under each heading would be manageable (Ziebland and McPherson 2006). QSR NVivo 2.0<sup>13</sup> was used to code and facilitate data retrieval by generating coding reports. Software packages for analysing qualitative can contribute to the rigour of analysis (Kelle, 1997).

The student and her supervisor regularly discussed whether the data being collected was generating new insights and made a decision to stop collecting data when nothing new of significance appeared to be arising.

## **4.11 Generation of meaning**

Ziebland and McPherson (2006) claim that 'once all the data have been coded, the real analysis can begin'. All the excerpts that have been coded under a heading are gathered together by the generation of a coding report. The aim of the next stage of the analysis is to ensure representation of all the different experiences and accounts in analysis. Ziebland and McPherson (2006) have termed their method for doing this 'an OSOP (one sheet of paper) analysis'. An OSOP analysis works much like a mind map. All the issues noted in the coding report are noted on paper along with the participants' ID number. At this point the OSOP is a one page summary of the coding report which is used to aid consideration of potential groupings of codes and explanations for what is occurring. At this point the researcher is seeking order and 'a story' from the data. Care was taken to ensure nuances remained intact and many quotes were left in place in the OSOP documents. Separate OSOPs were developed for the first and second interviews to facilitate comparisons between the two stages of participants' experience.

---

<sup>13</sup> <http://www.qsrinternational.com>

It was at this point the literature was read to see how the study findings compared to current understanding. Consideration of the findings were also possible through reading more widely and through discussions with colleagues. During this process a plausible order and narrative for the study findings began to take shape.

## **4.12 Chapter summary**

In this chapter development of the qualitative methods and theoretical base for this research project were detailed. Qualitative research, using in-depth interviews, was the most appropriate way to address the research questions of the study, particularly given the exploratory nature of the inquiry. The next two chapters present colorectal cancer patients' descriptions of their experience, and in particular their experience of health care.

## 5 Findings

### 5.1 Findings introduction

This findings chapter, the first of two, is structured to broadly correspond to the structure of the first part of the literature review which looked at the qualitative literature. Here the physical, psychological and social experience of colorectal cancer described by participants is examined. Within these categories findings are described ‘at diagnosis’ and then at one year after diagnosis. ‘At diagnosis’ refers to the time around diagnosis as was discussed at the first interview and typically spans the diagnostic event and treatment. Participants’ age refers to age at first interview.

### 5.2 The physical experience of colorectal cancer at diagnosis

The physical experience of colorectal cancer encompasses physical symptoms of the illness recalled at first interview and the effects of treatment.

#### 5.2.1 Experiencing the symptoms of colorectal cancer

Descriptions of symptoms which had lead to diagnosis were typically offered as the starting point for participants’ accounts of their illness and treatment. Changes in bowel habit were described and included: increased frequency of bowel movement; changes in consistency of stool; constipation; increased flatulence and faecal urgency. These changes were often accompanied by stomach pain.

When I went to the toilet I knew it wisnae right because I was never finished doing the toilet. –Meg, age 65, (1/2)

I used to get a sort of diarrhoea slackness and I thought, this is no me and I wasn’t too happy about it. –Charlie, age 72, (1/2)

I started passing motions that were black and eh uncontrollable. –Harry, age 81, (1/2)

The stool was sort of misshapen it wisnae like what I had been producing before. —Andrew, age 55, (1/2)

Blood in stools was usually considered to be a symptom that warranted consulting the GP about, however, there were a couple of cases where blood in stools was dismissed. In one case it was assumed to be caused by piles, and in another case it was assumed to be benign because the same symptom had been investigated previously and found to be benign.

Some participants were aware that their symptoms were suggestive of colorectal cancer. Clive recounted identifying with a television campaign to raise awareness of symptoms of colorectal cancer. However, some participants were unaware that their symptoms signalled cancer and had consulted because they were uncomfortable, painful or their symptoms were out of the ordinary. Charlie believed his symptoms were ‘not anything serious’ because they did not fit with his understanding of symptoms of colorectal cancer.

There wasn’t any bleeding or pain, so this is why you thought, well, it’s not anything serious. —Charlie, age 72, (1/2)

Bowel symptoms were sometimes assumed to be associated with diet or with other illnesses. Diarrhoea was believed to be caused by an increase in fruit and vegetable intake. In one case increased flatulence was also attributed to a diet high in fruit and vegetables.

Some participants did not have any bowel symptoms but consulted with symptoms suggestive of another problem or more vague indications of a problem, for example, pain or tiredness. Scarlett’s only symptom was tiredness and she assumed she was anaemic. Stephanie visited her GP because of ‘tummy ache’ and a pain in her side (which became increasingly painful as time passed and was confused for Irritable Bowel Syndrome (IBS)). Danny thought he had a urinary tract infection.

I had what I thought was a urine infection, and, em, actually, I’d had one many years before and so knew the sort of symptoms and, em,

got an appointment in December and was prescribed antibiotics just to treat that. –Danny, age 51, (1/1)

Jason was keen to highlight the mildness of the symptom which he had consulted about.

I thought it was a wee stitch in my side, you know. It was just like a wee nuisance. –Jason, age 76, (1/1)

When participants reflected on the period leading up to their diagnosis they wondered if there had been signs of their colorectal cancer which they had not, at the time, felt indicated an illness. These were vague symptoms such as tiredness, lack of energy, loss of interest in things and irritability, or symptoms which participants assumed to be self limiting or benign, such as diarrhoea.

I also, at one point in the autumn, felt exceptionally exhausted but that's nothing new for me and I put down the sweats which came and went over the period to just being my age, really. So I don't know whether they had any bearing at all, no idea, probably not. –Philippa, age 64, (1/2)

Some people were able to identify a gradual decline in their wellbeing in the months leading to diagnosis when they compared it to how they felt after treatment.

### **5.2.2 Experiencing surgery for colorectal cancer**

For many participants the time they felt least well was during their hospital stay. Participants described feeling terrible pain on waking from surgery which was usually dealt with speedily by intravenous pain relief. However some participants reacted badly to the pain relief either feeling very nauseous or becoming very unsettled and confused by the hallucinations it caused.

I said to the nurse there the last time, it was the same nurse you get at night, I says 'You and I must have a talk and I'll tell you what I thought I was doing (Laughs) and you can tell me what I did do'. But,

you know, it was funny, it was a peculiar situation, that, where you start to dream queer dreams. –Harry, age 81, (1/2)

Pain was an issue again as pain relief wore off and intravenous pain relief was withdrawn.

See the pain, and in the intensive care they were wonderful cause you're doped up to the eyes, you know, you don't feel anything but after it, like the medication starts wearing off, the pain is horrendous, absolutely horrendous, it's awful. –Tracey, age 46, (1/1)

Participants' bowel function was unpredictable immediately after surgery and lead to 'accidents' for some. Some experienced pain as their bowels began functioning for the first time after surgery.

Oh wind—I was in agony wae wind, now that I think about it after the operation, because they did say there might be wind, you know, and it was sore, it was painful and then the first time I had a motion it was agony, as if you were awful constipated, you know, but eh it was pretty bad. –Doris, age 84, (1/2)

### **5.2.3 Recovering from surgery for colorectal cancer**

Recovery from surgery involved a number of physical issues including bowel dysfunction, pain, sexual difficulties, weight loss and problems with wounds. Sometimes participants were readmitted to hospital because of post operative problems.

At home, after surgery, participants experienced problems of digestive dysfunction including: reduced bowel control; faecal urgency; faecal incontinence; increased frequency of bowel movements; diarrhoea; constipation; and increased flatulence. Participants could suffer from more than one digestive dysfunction issue and the issues they experienced were prone to change in the weeks following surgery.

Some reported problems readjusting to eating after surgery. These problems were most prominent in the weeks immediately after surgery and were linked to the digestive dysfunction they were experiencing, for example, certain foods could result in constipation, diarrhoea, flatulence or stomach pains. Conversely some enjoyed a return to regular bowel function very soon after surgery.

That's what I'm saying, you could set your watch. —Jason, age 76,  
(1/1)

Pain was a feature in the weeks following discharge. Some participants described painful throats persisting for a week or two after surgery. Discomfort at the site of the wound was reported by some during this time, but was described in terms of 'tenderness', 'pulling', or 'twangs' rather than pain.

Back pain, attributed to the surgery, caused problems in the case of two male participants. Hugh was experiencing lower back pain which he thought had been caused by surgery and the side effects from the pain killers that he was taking to relieve the back pain.

If ma eyes looked a wee bit—it's because I've had my painkillers,  
lower back is killing me, man, so it is, Susan, you know what I mean.  
—Hugh, age 48, (1/2)

Samuel said his sore back meant he was unable to stand for long enough to make a cup of tea. Berta reported an exacerbation of previous back pain and the onset of a pain running down her leg which she believed had been caused by surgery. Berta also had talked about a pain 'in her side' as did Maisie who described the elaborate ways in which she changed the way she moved in order to avoid triggering the pain.

Sexual issues had arisen for both men and women as a result of surgery. A couple of the men had been unable to achieve erection since surgery. Geoff was not concerned about this as he felt his physical relationship did not require intercourse but Andrew hoped to resume his sexual relationship with his wife.

Also trying tae resume a sexual relation with my wife again which I found great difficulty... I think we were getting to the age where, you know, it starts tae tail off a bit anyway, your sex life, eh it would be nice tae have it noo and again right enough—tae have the option... But definitely the operation has done something. —Andrew, age 55, (1/2)

Kirsty, who had a stoma, wondered at her first interview whether feeling self conscious about her physical appearance would hinder her sexual relationship with her partner.

Although weight loss was not described as a symptom of the illness by any of these participants some did lose weight during their treatment. Sometimes the weight loss occurred during their hospital stay when participants felt too unwell to eat much in the days following surgery. Chemotherapy could also result in weight loss with participants feeling too nauseous to eat at certain times during their chemotherapy cycles.

Wounds from surgery were frequently discussed, usually in a positive context to note that they were healing well, and, where participants had had laparoscopic surgery, in terms of how small the external scar was. There were, however, some cases where wounds had been slow to heal and or had become infected. Andrew was surprised that he had developed an infection as his wound had appeared to be healing well. He ‘had a wee leakage of the rear end wound’ for which he was given antibiotics, however he then developed a rash and, consequently, the antibiotics were stopped. At the time of first interview Andrew felt that his wound had improved. He had previously been unable to sit and was now able to sit and eat a meal with his family. (At Andrew’s second interview he reflected that the he may not have reacted badly to the antibiotics but rather to the pain relief he had been taking.) Pain at the site of the operation was experienced by some and was an issue at first interview some weeks after surgery.

I’m still really raw inside—I’ve got a lot of pain here. —Tracey, age 46, (1/1)



Some talked about being unable to move in certain ways if they hoped to avoid pain but most talked about a discernible decrease in pain since their discharge from hospital.

A couple of participants were readmitted due to complications after surgery. Stephanie was readmitted to hospital days after discharge because of a obstruction in her bowel and Harry because of an infection in the bowel. As a result of investigations Harry had undergone during his second hospital stay he had a sore and cracked mouth which made eating difficult.

They put a camera down my throat. Well believe it or not they didn't find anything and that has been worse because all my mouth cracked where they sprayed it, you know, and I wasn't all that interested in eating and trying to get these wee bits at the side to open up and eat. And that was probably more annoying than the actual operation (laughs). –Harry, age 81, (1/2)

Harry went on to have another admission when a urinary tract infection was diagnosed. Again, he felt too unwell to eat.

For most people the first interviews were carried out within weeks of their surgery and at this post operative phase their health tended to be in a state of flux. Participants experienced multiple physical issues simultaneously and as some issues were resolved new problems emerged.

I had some problems, you know, after the operation—I mean, having constipation so I've been given some medicines for that, and it was constipation, and after that going to the toilet many times... I have pain in my left side and sometimes there's pain on my whole leg, you know. –Berta, age 50, (1/2)

#### **5.2.4 The experience of chemotherapy**

The initial interviews were carried out within the first months after diagnosis and therefore a number of interviews were carried out during adjuvant chemotherapy so the experience being reported was frequently current.

Side effects from chemotherapy are described including: tiredness, exhaustion, pain, nausea, vomiting, diarrhoea, swelling of feet, painful and sensitive skin on hands and feet and an inability to tolerate extremes of temperature especially cold.

The severity of side effects varied with some reporting only mild nausea and manageable tiredness but more usually chemotherapy side effects were difficult to tolerate.

I'm feeling a lot better today and I'm going to feel a lot better as the week goes on but then I know by next Saturday when I come home I'm going to feel rotten again. –Scarlett, age 72, (1/1)

It's bad enough wae the pins and needles in my hand, wae anything cold I'm okay these four days, there's still a wee tingle, but the minute I go back on that on Friday I'm no going to be able to take anything cold, I'll no be able to drink anything cold, I'll no be able to touch anything cold, so it is quite hard to cope with because you cannae dae anything for yourself really. –Tracey, age 46, (1/1)

### **5.2.5 The experience of a stoma**

Those with a stoma, either temporary or permanent, did not seem to suffer any greater physical impact. Indeed participants with stomas were amongst those who reported feeling very well.

I feel I am almost back to normal at the moment which is only a few weeks after the operation. So hopefully if I keep improving the way I've done in the last few weeks I'll just see everything as the way it's been before apart from my wee bag. –Alice, age 69, (1/2)

Those with temporary ileostomies had to undergo a further surgery to have the ileostomy reversed and Teresa described recovering from the reversal as similar to recovering from her initial surgery.

It had taken a similar length of time to recover, she had felt weak and suffered from digestive dysfunction for a time but at her second interview she felt very well.

### **5.2.6 General wellbeing at diagnosis**

Participants were specifically asked to talk about problems they had experienced yet many were at pains to volunteer how well they felt and how their recovery from surgery had exceeded their expectations. This was the case even at the first interview when some participants felt they were already close to having regained their fitness.

So that was it, I was never up nor down. –Jason, age 76, (1/1)

I felt better than I thought I would ever have felt, you know, after having the operation, I thought it would be a lot worse. –Kirsty, age 37, (1/2)

At the time of the first interview some participants described themselves as feeling weak and lacking strength however, this was very much in keeping with their expectations of recovering from surgery and they were able to chart an improvement in the weeks since their discharge from hospital. Their assessments were augmented by a hope that improvements would continue until they were able to resume their normal lives.

It's just I'm weaker than I was but I'm getting stronger every day and I don't think that in general day-to-day living it will have a long term affect on me. I can see light at the end of the tunnel. I'm going to get back to where I was, you know, and live my life. –Andrew, age 55, (1/2)

However some participants were disappointed by the slowness of their recovery with two women comparing it unfavourably to recovering from other operations (a lumpectomy and a hysterectomy). Tracey described her frustrations at being physically compromised for a protracted length of time.

And I widnae wish it on anybody—I'm being honest, although the treatment's great the recovery period is quite difficult... I still cannae lift, like, heavy weights—I feel totally useless, really honestly, I cannae carry a lot of shopping my limit's about a loaf, a paper... I think there's a very, very long recovery period wae bowel cancer. — Tracey, age 46, (1/1)

Samuel's physical incapacity in the period following surgery lead to psychological difficulties that in turn further undermined his physical capacity.

I was okay and the next day I was an old man when I came out of my operation. All of a sudden, I mean, I couldnae do nothing, I wisnae interested in doing anything because I couldn't do it and the wife says I was in a sort of depression since I've come home because I've been terrible. —Samuel, age 81, (1/2)

### **5.3 The physical experience of colorectal cancer one year after diagnosis**

One year later participants' health had become more settled and predictable but most participants had ongoing physical issues. Fatigue and digestive dysfunction were the main ongoing issues into the second year after diagnosis.

#### **5.3.1 Experiencing the long term and late effects of colorectal cancer**

The long term and late effects experienced by participants included fatigue, bowel dysfunction, sexual difficulties, weight gain, problems with wounds and hernias, and chemotherapy and radiotherapy side effects.

When interviewed for the first time participants mentioned that they felt tired, but this was frequently a comment made 'in passing' implying the expectation that recovery from major surgery necessarily involves tiredness. By the time participants were interviewed for a second time fatigue and tiredness had evolved into a distinct issue which some portrayed as their most troublesome ongoing problem. Fatigue was described as unpleasant in itself and frustrating because it hindered participants' attempts to resume their normal lives.

But eh just huvnae got an ounce of energy, you know what I mean? –  
Maisie, age 64, (2/2)

I was so tired. I'm sick of moaning about it—I never, ever felt I'd be  
this tired, really, really, tired and I only do four hours (work). –  
Stephanie, age 53, (2/2)

Participants had not expected to be suffering from fatigue twelve months after surgery and wondered whether it was associated with their illness, or treatment, and whether it was normal.

I was still tired and to tell you the truth I'm still tired, sometimes I'm very tired, I don't know what that's to do with but at the weekend there I just felt absolutely exhausted really. So I don't know whether that's normal or what, I don't know. I'm abnormally—well at the weekend I felt I was abnormally tired, you know, I could hardly bring myself to do anything and it just sort of reminded me of the way I was when I came home from hospital, you know. –Glenda, age 67, (2/2)

Muriel, who suffered from sleep problems, mused that her sleep problems caused her fatigue whereas, for Glenda, excessive sleeping was a symptom of her fatigue.

Others thought that sleep had become a problem since their colorectal cancer diagnosis but they could not discern the precise cause and pondered whether it was physical or psychological in origin. Muriel had discussed her sleep difficulties with a friend who had had cancer and her friend recommended she ask her GP for a specific medication and she had done this. She thought that her sleep was improving somewhat on the medication.

For some, digestive dysfunction issues had become an ongoing feature of their lives, still current at their second interview.

Yeah, I think I suppose it's not one hundred percent fine after you have an operation, you know, because my bowels sometimes goes crazy... you know, but eh I wouldn't say 'Oh I have constipation, I have

diarrhoea' no it's just, you know, the times I have to go to the toilet and can be very bloated, you know, very gassy, very uncomfortable sometimes. –Berta, age 50, (2/2)

I had very great difficulty getting from here to the loo and I do have that. What I do have now often is the need to go to the loo—it wakes me up in the night—I have to go very quickly. I wake up and have to get out of bed and run to the loo and sometimes I have to stop on the way and clench everything and it's jolly painful. –Philippa, age 64, (2/2)

Participants' accounts of diarrhoea, faecal urgency and incontinence focused on strategies to cope in the context of resuming a more social and active lifestyle. A range of strategies were employed: participants used incontinence pads, planned activities to fit with their bowel habits, used medication (particularly when traveling), carried a change of clothing and developed an in-depth knowledge of the whereabouts of public toilets. For Hugh, however, his bowel problems were unmanageable at his second interview when he described himself as incontinent.

And I know how hard it is but it's happened tae me a couple of times, do you know what I mean and it's embarrassing to me, and I was never like that, you know what I mean. If I need to go to the toilet, Susan, I need to go to the toilet immediately if I'm not there, even though I'll go like that and it comes oot, do you know what I mean. – Hugh, age 48, (2/2)

There was a lot of discussion around diets which had been altered to avoid constipation, diarrhoea, wind and abdominal pain. Some people were only able to eat small portions if they hoped to avoid digestive dysfunction. Elsewhere people ate less as their appetite had reduced.

Sexual difficulties were an enduring feature. Andrew had been unable to resume a sex life with his wife and treatment with viagra had not helped him. At the point of the second interview his erectile dysfunction was an ongoing problem. (At the second interview Andrew said that he had been passing blood in urine,

and that Urology were investigating, and that the Urologist suggested it may be related to the surgery.) Lorraine had not mentioned sexual problems at the first interview but at the second interview she reported that intercourse was painful.

Kirsty's concerns regarding her sex life had proved unfounded and when she was interviewed one year later she described a healthy sex life which she attributed to her partner's assurances that he did not find her less attractive because of her stoma.

Those who had discussed their weight loss at the first interview reported having regained the weight a year later. Stephanie had been upset at extent of her weight loss at the first interview and although she had regained most of her loss by the second interview she felt her weight gain around her scar was 'misshapen'.

One year later some participants, who had not described weight loss in the first instance, talked about weight gain as a consequence of treatment. Doris thought her weight gain was the result of the more sedentary lifestyle she had led since her operation: she felt she had not regained the strength she had before her surgery and she also suffered from painful arthritis. Some participants were unhappy about their weight gain and were having difficulties in their attempts to lose weight.

The other thing is I put on a lot of weight well over a stone about a stone and a half while I was having treatment. And everyone—I mean the medical people said 'Oh that's good' but it's not so good for me in that I'm still overweight and I cannot shift it. —Glenda, age 67, (2/2)

One year later discomfort associated with adhesions at the site of the operation were described but to a much lesser extent than previously. A few participants had developed hernias on their wound. One man had had surgery to remove a hernia but for others there were no plans to remove hernias. Hernias tended not to cause pain although some participants described mild discomfort and some described very large hernias.

I mean if you cough it disnae half come oot you've got to sort of haud it back in, you know, you feel it's gonnae bust but there's no pain with it. –Samuel, age 81, (2/2)

Chemotherapy had been completed by second interview and was vividly remembered by many as an especially challenging time.

The sicky feeling and oh the nausea, oh. At the time, while it's going on, and then like I would be really ill for about three days after I had it, and then I would kind of pull myself out it, you know, but it actually took about a week tae come through it. But the three days were horrible, they were just horrible. –Meg, age 65, (2/2)

Lorraine endured significant pain throughout her course of chemotherapy. Her IV regime was switched to oral after a frightening accident with her PICC line.

Well one night my PICC line, I suddenly felt a sharp pain on my elbow and I looked down and the PICC line was gone, it got stuck into my body (laughs) and I had to go through an operation where they went in through my main artery and my groin and whipped it out. –Lorraine, age 34, (2/2)

Lorraine had less pain from oral chemotherapy but still had problems tolerating cold temperatures.

It was cold. I couldn't go out in the cold. I couldn't obviously wash my hands underneath cold water. I couldn't drink. And I actually had one incident where I thought was going to die because I went out in the cold from the hospital out to the car and before I got in the car I stopped breathing, you know, the side effects of Oxaliplatin your airways can actually close. –Lorraine, age 34, (2/2)

For some the side effects of adjuvant treatment were in the past but for others chemotherapy had a more enduring physical impact. Glenda remained unable to tolerate extremes of temperatures in food and drink and a couple of participants said that they were only starting to regain the feeling in her hands nearly a year



after their courses of chemotherapy had been completed. Stephanie blamed her frozen shoulder on chemotherapy. Lorraine suspected that hot flushes and feeling 'a bit moody' were signs of menopause brought on prematurely by her adjuvant treatment. Andrew had teeth extracted because of dental decay which his dentist suspected was to do with chemotherapy.

Fewer participants had undergone radiotherapy and, for those that had, the side effects were usually temporary and included tiredness and a burning sensation. Jacqueline described a 'colicky burning sensation' still present at second interview.

There were some permanent repercussions from radiotherapy. Lorraine talked at the first interview about being made aware that radiotherapy would result in infertility. Stephanie had radiotherapy after her surgery to treat liver mets and had been told that her right kidney would cease functioning. She said that her left kidney had been tested and would be able to compensate when this happened.

### **5.3.2 General well-being one year after diagnosis**

At the second interview some participants said they felt better than they had felt in some years, indicating a full recovery from illness (which had been playing on them for quite some time, unbeknown to them).

Well, I would say I'm better than I was prior to the surgery definitely, oh aye. —Alice, age 69, (2/2)

Most participants had regained their strength and fitness to a degree that enabled them to resume their normal lives. This had required a strategic effort from some who had incrementally increased the amount of exercise they did.

I said 'Look I'm going to start running', so I started running and I worked from running one minute, walking two minutes to running twenty minutes like alternatively, that was in a month or six weeks or something, right. —Lorraine, age 34, (2/2)

Most ongoing issues had been accommodated in people's lives but some voiced disappointment that they did not feel as well or as strong as they had prior to their illness. Fatigue posed the greatest barrier to the resumption of normal life. Age was described as a confounding factor, for this older sample of patients, in trying to understand the physical impact of colorectal cancer. Where people believed they had slowed down they queried whether it was because of colorectal cancer or if it would have occurred anyway, as they got older.

## **5.4 The psychological experience of colorectal cancer at diagnosis**

A diagnosis of cancer brings to the fore the prospect of death which may be challenging to cope with. Effort is required to understand and assimilate the diagnosis and many questions arise regarding the cause of the illness and prognosis. The psychological experience is so profound that participants' sense of themselves is called into question.

### **5.4.1 A diagnosis of colorectal cancer**

The psychological challenges participants faced on being diagnosed began with dealing with the shock of diagnosis. People said they felt 'shattered', 'stunned', 'shocked', 'traumatised', 'frightened' and 'numb'. They said that the diagnosis was 'pretty ghastly', 'blew us away', and that their 'whole world collapsed'.

The Doctor, she just cawed the feet from us, is the only explanation.

—Alice, age 69, (1/2)

I must say that was really awful and I was shaking, really shaking. —

Philippa, age 64, (1/2)

I mean, I felt really weird, I felt disassociated from it all. —Glenda,

age 67, (1/2)

Muriel was upset because she had had breast cancer two years previously and thought that a second cancer diagnosis was particularly traumatic.

The diagnosis of colorectal cancer was often entirely unexpected. Some were surprised because they believed their symptoms were due to another ailment, for example, Scarlett thought she felt tired because she was anaemic and Jacqueline had ignored rectal bleeding believing it to be due to haemorrhoids. Alice was surprised because she thought colorectal cancer had been ruled out as a possibility when a faecal occult blood test (a test which can detect tiny amounts of blood in faeces) returned a negative result. Even if participants had suspected colorectal cancer themselves, or if the possibility had been suggested by health professionals, the diagnosis still proved shocking.

Although I knew he was going to say that, it still was a wee bit of a shock. —Meg, age 65, (1/2)

You don't believe the worst until you actually hear the worst, you know. —Clive, age 59, (1/2)

Some participants talked about crying, shaking or ceasing to hear what was being said during their diagnostic consultation. But there were others who said they'd felt calm on learning their diagnosis.

It's strange though, I mean even when they told me, I can't say, it's a strange feeling, I didn't feel frightened or anything. —Scarlett, age 72, (1/1)

Occasionally the diagnosis was described as a relief: being aware of a cancer diagnosis was less consuming than suspecting cancer.

It's not constantly coming into my mind. Whereas when I didn't have it and I thought I might have had it, it was constantly in my mind. —Clive, age 59, (1/2)

As long as I know what it is, aye that's it, it's the waiting. —Geoff, age 75, (1/1)

When you don't know if it's really malignant or how more in your body. It is you don't know. I think that is the worst part until you know. –Berta, age 50, (1/2)

Lorraine's calm response led her surgeon to ask her whether she realised the diagnosis was serious. The idea that having been prepared for the diagnosis by medical staff had lessened the impact of the diagnosis was suggested by Kirsty.

I wasn't upset in the least because I think I knew when she told me the fortnight before it was a bit sticky and what it meant, it kind of prepared me for what was coming. –Kirsty, age 37, (1/2)

However, even where participants had felt, or behaved, calmly the diagnosis was still a most significant event and the dialogue between the participant and health professional was remembered and reiterated in detail.

He said 'Well you know it's a polyp and you know there can be two kinds of polyps and one can be cancerous or it can be non-cancerous' and there was a kind of a silence and I said 'And is mine cancerous?' and he said 'Yes it is.' –Glenda, age 67, (1/2)

These diagnostic consultations were described as following a pattern whereby a diagnosis of colorectal cancer was given and then a plan for treatment proposed. Often participants said it was this immediate focus on treatment that allowed them to consider that their diagnosis may not have the catastrophic consequences they had initially imagined.

You've heard that many stories, and somebody saying they've got cancer but they're just trying to keep it down the now, and that kind of thing. So he gave me that feeling that, oh this is, so I think that word that he said 'We're hoping for this to be cured' and I think that I kept jumping back to that. –Meg, age 65, (1/2)

Well that was me kind of floored then, you know, because I didnae, I cannae get that, you know. And eh he started explaining and we asked him 'Whit you gonnae do?' and he said 'Oh you're coming in

next Monday and I'm gonnae take it out on Tuesday'. –Jason, age 76, (1/2)

What was actually considered to be the diagnostic consultation varied. Some described their diagnostic consultation as the investigation where the suspicion of cancer had been raised. In these cases the results of the biopsy, which came later, were mere administrative details. For others, receiving the definitive biopsy results, when the cancer was confirmed, was their diagnosis. Tracey fell into the latter category, and received her biopsy results by 'phone as she walked to work.

She said to me 'I'm just phoning to tell you it's cancer'—I burst out crying in the street and I was just there myself and there was an old pensioner, a wee man, and he came along and says 'Are you alright lass?' and I said 'No, I don't think so I've just been told I've got cancer' and the wee man said 'Oh I don't know whit to say to you' and I said 'I don't know whit to say myself'. But I wiped my eyes and I went about my job. –Tracey, age 46, (1/1)

The hours immediately following diagnosis were also remembered and reported in detail. The shocking nature of the diagnosis meant that most people wanted to go home and absorb the news.

He said to me, 'Do you want to ask me anything?' and I said, 'No, I just need to get home now to get my head round this'. –Meg, age 65, (1/2)

Absorbing the news could involve taking time alone to think about things and not to talk.

So, however, when I got home and I wisnae really discussing it, it's funny. –Meg, age 65, (1/2)

When I got home that day I just didn't want to talk about it, I sat and I read the paper from beginning to end and I sat and I read a book and I just didn't want to talk about it. –Teresa, age 70, (1/2)

Elsewhere talking about the diagnosis, about the planned treatment and about the potential ramifications of the illness was preferred.

After the shock of the diagnosis had subsided it was replaced by a determination to 'get through' and 'survive' and for treatment to commence.

I just felt well lets do something about what's to happen—let's get on with it. —Scarlett, age 72, (1/1)

Gradually, we were more or less dumbstruck, when we came round, as I would say, we just decided we're going to get over it, make the best of it and that's it. —Teresa, age 70, (1/2)

After a period of time, sometimes hours, more usually days, the shock subsided. Jacqueline experienced devastation on learning about her colorectal cancer and this was magnified by a chance remark from a nurse that 'miracles could happen'. Yet in the same day her doctor's optimism and a fellow patient's telling of how her sister had survived colorectal cancer made her feel that 'this could be alright'.

In the weeks following diagnosis the calm response of some evident from the outset continued. The interviews suggest the possibility of finding the news shocking yet remaining calm. Some participants had surprised themselves and those close to them by remaining clam.

In my mind I feel fine. Can you believe it? —Meg, age 65, (1/2)

They say, 'Oh, I don't know how you can, you're so strong and positive' and I'm like, 'You would be' and they're like that, 'Oh, I don't think I would be'. But I said 'You would be if it had happened to you'. —  
Kirsty, age 37, (1/2)

When asked about their calm response the idea of whether participants had any control over their future was suggested. But it could work either way, for example, Charlie suggests his own agency in compliance with his treatment plan.

I said 'Well, can we do anything about it?'. She says 'Yes'. I said 'Well, come on'. That's the way I've come through it. —Charlie, age 72, (1/2)

Whereas Doris attributed her calm response to her Christian faith, specifically, that her future lay outside her control.

#### **5.4.2 Making sense of a diagnosis of colorectal cancer**

Participants felt that they had a good understanding of their diagnosis and described time and efforts that health professionals had taken to ensure their understanding. Most had known little about colorectal cancer prior to diagnosis and most learning had taken place during consultations with health professionals.

Part of the challenge of making sense was the struggle to understand what had caused their cancer. There was mention of diet and exercise as causal factors but usually in the context of interviewees feeling bewilderment about the cause of their cancer (because they had eaten well and exercised). However Tracey did attribute her cancer to her habit of eating take-away food.

Familial susceptibility was mentioned with some participants having a sense of a hereditary disposition to colorectal cancer based either on knowledge of family members who had had colorectal cancer or of family members who had had other cancers. Andrew believed people could be born with cancer.

Philippa wondered if venison her family had eaten, which would have come from a part of Argyll affected by rainfall from Chernobyl, may have been to blame. But she was more convinced that recent stress she had experienced had played a part.

I feel in my mind that stress has been very much implicated in the cause of this and that, if there is immune compromised, it's in the gut. —Philippa, age 64, (1/2)

Making sense of the potential for a cancer diagnosis to be a terminal diagnosis sits as a subtext to participants' descriptions about how they felt and how they coped. The synonymy of cancer with death is more often implied than expressed, but the interviews are dotted with some explicit references to death. Meg described initially interpreting her diagnosis as being terminal. Berta's references to graveyards make clear her fears and Hugh thought everyone understood cancer as terminal.

If I'm being honest when I first heard it I thought, 'that's it'. That was the thought, I think, that was in my head, 'well, everybody's to go some way' —Meg, age 65, (1/2)

I didn't want to see any cemetery, any place like that, or graves. I was just oh, you know, everything was, I don't know how do you say, oh terrible for me, my feelings. I was thinking of my child. —Berta, age 50, (1/2)

It's the word itself, 'cancer'. Do you know what I mean? That's the killer—it's oh no, you know. Everybody's like that—the whole family, cancer, death, do you understand? That's what people think. —Hugh, age 48, (1/2)

Meg described wondering, at one point, if she would be part of a spate of cancer deaths. As Meg waited for her diagnostic consultation she thought about two people she knew who had died shortly after being diagnosed with cancer. These people's proximity in age was enough for Meg to conclude 'it must be'.

Believe it or not, the months before I heard about this one, you know, different people, she's just back her holidays, away a cruise, come back from her cruise, went to her Doctor and she's got weeks. Then, you can believe this, then the next thing it was somebody I used to work beside, and she had went to the Doctor, weeks to live. Oh I don't believe this. Then when, of course, when I went in and I'm saying, 'well we're all about the same age and these things have happened to them—it must be'. —Meg, age 65, (1/2)



Jacqueline and Lorraine talked about the worrying about death in the context of worrying about their families.

I mean, there are two main things I want to survive for is my kids and my husband. –Lorraine, age 34, (1/2)

That's the main thing for my family. I couldn't bear the thought of having to leave them on their own. –Jacqueline, age 55, (1/2)

And Danny, who was receiving palliative treatment, talked about the impact of the prospect of death on his mood.

I just as I said won't be dragged down by the thought that things might all go wrong and I won't be here soon. –Danny, age 51, (1/1)

Some participants said that they believed their diagnosis was not terminal, either as a result of information from health professionals, or because of their own 'hunches'.

The speed at which treatment plans were outlined and initiated were noted by many and some thought this was a key factor in allowing them to cope.

I think the fact that by the time I realised it was cancer, I knew I was going in to be operated on. –Scarlett, age 72, (1/1)

I was in on the Friday and got the scan, I was back on the Monday to get the results and I was back on the Friday to get the all over scan and I was back on the Monday and the job was done on the Tuesday. So I never really got time to, 'God, I've got cancer' you know, 'you die wae that' I never gied that a thought— everything was going that quick. –Jason, age 76, (1/2)

Occasionally the pace at which investigations and treatment took place caused concern. Teresa interpreted the fast pace as cause to wonder whether she had interpreted her prognosis correctly. Maisie asked that her surgery be delayed by a few weeks as she found the prospect of surgery frightening.

Frequently participants would describe a shift in their thinking from, at the outset, understanding of a cancer diagnosis as a terminal diagnosis to, later, an understanding of their diagnosis as treatable. In a couple of cases understanding the diagnosis as not terminal appeared to require understanding the diagnosis of cancer as a misnomer. Both Philippa and Kirsty thought that the label of cancer did not really apply to them.

I would like to start actually by saying that I don't think I had cancer. I had a very small, very early, em, I had a polyp which had, which was very small and very early cancer, how can I make that clear? –  
Philippa, age 64, (1/2)

I just keep thinking it's a polyp I've had, you know. You don't think it's like, I mean, you just think cancer as in this big, you're riddled with it, this big tumour. Whereas I've no had really that. But I suppose even still having a wee tiny bit—it's been somewhere in your body, it's obviously still classed as cancer. –Kirsty, age 37, (1/2)

After learning their diagnosis participants underwent additional investigations to ascertain the extent of their colorectal tumour and whether their cancer had metastasised. Understanding of the potential implication that spread of cancer would have on prognosis was varied but the majority understood a contained tumour in one site to be associated with a better prognosis. Therefore undergoing these investigations and waiting for results could lead to anxiety.

I couldn't cope because, he didn't know I couldn't cope because I carried on as just as normal but I would lie in bed at night and I would say, 'Oh dear God, please don't make it go through all his body' –  
Geoff (wife) (1/1)

Even after surgery Maisie continued to worry.

She said that they got everything but I don't know, I would just like to know when I could get another scan. –Maisie, age 64, (1/2)

When Jacqueline felt unwell soon after surgery she worried that it was due to an undetected tumour in her liver.

I was starting to really panic because I had been sick and I was totally convinced something was wrong with my liver and that this had spread and this was why I was being sick and I just became totally paranoid.

—Jacqueline, age 55, (1/2)

Scarlett had not known about the potential for spread and so was unusual in that she did not worry.

That was a thing that had never occurred to me. Never occurred to me and when Mr X was telling me that it was contained in the bowel and hadn't touched the liver or the kidneys and I looked at him. It never occurred to me that it would. So I suppose ignorance is bliss really. —Scarlett, age 72, (1/1)

The possibility of the cancer recurring was another source of anxiety. This could be talked about in the context of the anxiety itself being an issue that needed to be controlled.

I say to myself, 'well, don't concentrate on the people whose cancer has come back—concentrate on the people whose cancer hasn't come back'. —Glenda, age 67, (1/2)

I'm aware that it is possible that a stray cell has gone astray but they will find it and I intend to live believing that they won't and if they do it will be very, very early. —Philippa, age 64, (1/2)

Kirsty found the prospect of follow up, the idea that she would be closely monitored, reassuring.

They'll keep such a close eye on me. I'll get checked up quite often to begin with so I feel as if I'm in good hands, you know. I'm probably in a better situation than Joe Bloggs next door. —Kirsty, age 37, (1/2)

Elsewhere participants managed their fears by understanding the experiences of others who had ended up with good outcomes as analogous to their own, and underpinning hopes that they, too, would enjoy positive outcomes.

Philippa makes a very straightforward conjecture that her friend's good outcome, in spite of having been diagnosed at a more advanced stage, boded well for her (diagnosed with Dukes' A).

I know a lot of people who know of, or know a lot of people, who had it really badly. I mean have had actually bowel cancer and are really fantastically well. One great friend had it extremely badly. She had a Dukes' CB, I think, which she was told, a long time later, was very bad indeed. So, that was very good for me. —Philippa, age 64, (1/2)

Participants were able to use accounts of other cancers in developing their case for survival.

I know quite a few people that have had breast cancer, of my friends there's about three of my friends that have had it and they are all doing really well. And so that has, you know, given me some confidence. —Jacqueline, age 55, (1/2)

Tracey also borrowed from others' experience to illustrate her expectation of survival.

One of my clients' brother, he had bowel cancer and he was diagnosed in his fifties and he lived tae he was eighty. —Tracey, age 46, (1/1)

Elsewhere, Tracey tracks the similarities in her case and someone she met from similar adjuvant treatments right through to survival.

I was talking to a wee woman the other day she had breast cancer fifteen years ago and it has never, ever come back and she's on the same as what I'm on—she's on tablets but she got a wee dose of radium for two months and something and it's never, ever come back.

She went, 'So, Tracey, there is quite a high success rate nowadays' you know. –Tracey, age 46, (1/1)

Experiences ending with poor outcomes were presented as analogous to the participants' experiences to a point, then a key difference is identified allowing the narratives to diverge and so that participants' hopes of survival are sustained. In spite of Meg's experience of close family members dying of cancer she imagines a different outcome for herself.

I've had a brother that's died wae cancer. I've had a mother that's died wae cancer. And my brother he just went wae a pain in his shoulder, right, but it was, he had just maybe a couple of months or something. And so it's no that I don't thingmy but for some reason, some reason, I don't know why, but I don't feel, I just feel fine. – Meg, age 65, (1/2)

Tracey points to advances in treatment to underpin a rationale that her cancer will not prove terminal.

I lost ten in the family wae cancer. But in they days there was nothing. –Tracey, age 46, (1/1)

Muriel provides reasons why her outcome will differ: treatment has advanced and her positive outlook will impact her survival.

My mother had lung cancer many years ago and I know at that time they hadn't come on with any of the cancer research to the extent they have nowadays. And I've just tried to always keep a positive attitude towards it and make up my mind that I'm going to get better. –Muriel, age 68, (1/2)

### **5.4.3 Coping with investigations and treatment**

Other anxieties around investigations and treatment were described. Meg found the idea of further scans frightening. Some had been fearful of surgery specifically about whether a stoma would be required, about complications with

surgery and about surviving surgery. Others were anxious about the prospect of chemotherapy. Scarlett, for whom chemotherapy had commenced, became anxious during each cycle as the prospect of feeling unwell again loomed.

I'm going to feel a lot better as the week goes on but then I know by next Saturday when I come home I'm going to feel rotten again. That's the hard bit but I don't think there's any way round that. You've just got to face that and say, 'Right, seven days I'm going to feel like this'. –Scarlett, age 72, (1/1)

Treatment plans were usually described to participants without much requirement for input from participants. In a couple of cases where input was required this caused anxiety. Meg was asked to decide between chemotherapy delivered orally or intravenously. She would have preferred not to have had to make that decision.

I wanted somebody to say, I wanted them just to say, that's the way it's to go. –Meg, age 65, (1/2)

Lorraine had struggled deciding whether or not to go ahead with radiotherapy because she had been very unhappy when she had learned it would render her infertile. However, after discussing it with her surgeon she found her choice straightforward.

So, finally I went back to see the surgeon again and I said to him, 'Look, tell me why I should take the radiotherapy?' ...So, I mean, basically the way he put it was like 'if you don't take this you could land up dead', I mean he didn't say that but I knew what he was saying... At that point when he said that I made up my mind there and then on the spot I was like 'no, it's not worth it, it's not worth it so that I can have children, another child to be dead for these children'. –Lorraine, age 34, (1/2)

Maisie described feeling abandoned after her hospital stay. She felt confused about her follow up, when it would commence and what it would involve. She

planned to phone the specialist nurse to find out when she would next attend her clinic.

I wisnae sleeping but I've started it again, getting up sitting, cause I'm worrying during the night mair than during the day and I don't sleep very well so I keep saying 'I'll phone, so I will phone her and have a word wae her, you know what I mean?' ...I think you're just in tae get the operation you're flung oot and that's it. –Maisie, age 64, (1/2)

#### 5.4.4 Changed identities at diagnosis

To identify as a person with cancer represented a change in participants' sense of themselves.

For two months we were going to bed at night saying 'He's got cancer' you waken up in the morning 'He's got cancer' you're going to the shops 'He's got cancer'. You're living, eating, sleeping, drinking it. – Geoff (wife) (1/1)

Criteria for being a 'cancer patient' varied between participants and the label ceased to apply to some as soon as they'd had surgery. Others felt that cancer would continue to define them in spite of assurances that the cancer had been removed.

I feel I'm a person with cancer even though (the nurse) told me 'Glenda, you don't have cancer, it's gone and the margins were clear and you've had what's called a good cancer operation'. I still feel I'm a person with cancer and I don't know that I'll ever not feel that now truthfully. –Glenda, age 67, (1/2)

A person with cancer was clearly how some participants were perceived by other people and in Scarlett's case this was at odds with how she felt about herself.

I never think 'oh I've had cancer'. I don't think like that, you know. I just don't and, you know, sometimes peoples reactions, you know,

they 'Oh how are you?'. And you think, I mean, 'Well I've had the operation and I'm fine, I'm going to be fine now'. –Scarlett, age 72, (1/1)

Participants talked about changed thinking in a few areas. Some said they would be more likely to indulge themselves, enjoy life, 'make the most of it' and 'live for the moment'. Muriel said she would be more likely to spend money on things she wanted. Meg and Glenda believed they would be more likely to do things they wanted to than previously. Some talked about feeling appreciative, fortunate and 'glad to be alive'.

I'm glad tae be here recording this. –Andrew, age 55, (1/2)

Meg and Philippa said they would consult a health professional, or advise a family member to consult a health professional, much more readily than previously.

One thing that I think is extremely important to take from it—but I knew it anyway—is not to ignore medically something that you think might be significant. –Philippa, age 64, (1/2)

Both Andrew and Stephanie felt more emotional and more susceptible to crying.

I find things that might not have moved me before I'm actually quite emotional, you know. Watching movies and things like that if it's a really sad bit, you know, you feel the tears. –Andrew, age 55, (1/2)

#### **5.4.5 Psychological struggles**

The interviews contain some accounts of real struggles to cope and mentions of depression. The limitations that the illness imposed on participants' lives could lead to feelings of depression. Scarlett said that being confined to her house because of the side effects of chemotherapy made her feel depressed. Tracey described a very active lifestyle before her diagnosis where she had walked a lot and done a physical job.



I just feel absolutely totally useless, you know. It's a horrible, horrible, feeling. Now I know how an old person feels—see when I'm walking along the street, I actually know how an old person feels now. This must be what like it is when you're older. It is horrible, everything's got to slow down, everything's got to go at a snails pace.  
—Tracey, age 46, (1/1)

Samuel's wife had thought him depressed when he had returned home after surgery. He attributed his low mood to being unable to do what he had previously done in terms of his domestic routine. He felt his mood had lifted by the time the first interview took place.

I mean, I couldnae do nothin. I wisnae interested in doing anything, because I couldn't do it. And the wife says I was in a sort of depression since I've come home because I've been terrible. I don't mean fighting and things like that but I think I'm moaning and groaning. —Samuel, age 81, (1/2)

Clive said that he had wondered if he would need anti depressants, and he did allude to still feeling something that 'is probably more a depression than, you know, than anything else', but he was not keen on the prospect of anti depressants.

Stephanie gave accounts of struggling with her emotions.

I do have my moments, my weaker moments. I was upset yesterday. (Crying) I was trying clothes on and they were a size ten and in fact one of the skirts wouldn't fit me and I got a size eight (Crying) cause I was so thin and that upset me. Apart from that I was just looking so thin so I need to fatten myself up, fatten myself up by Christmas—that's what I'll do. —Stephanie, age 53, (1/2)

No one who described a low mood had spoken about it with a health professional. Indeed, efforts were made to disguise difficulties participants were experiencing even to family and friends. This could be to save those close to the participants from worry. Jacqueline said she hid her fears about dying from her

family and made an effort to appear upbeat in their company. Meg ‘put a brave face on things’ and made a particular effort to hide her fears when she was being scanned because she thought if her husband saw how frightened she was, it would affect how he would feel if he ever had to undergo a similar procedure. Glenda’s fears of recurrence were not mentioned to her family.

My cousin had breast cancer and then she got it again, except it was a different type and so that’s in my mind a lot but I don’t say that to anyone. I don’t say that to the boys or to (husband). —Glenda, age 67, (1/2)

The idea of being forthcoming about finding the illness difficult, to those who enquired, seemed alien to some. Teresa thought that her GP should have visited her at home after her surgery in order to get beyond the superficial ‘Oh I’m fine, I’m fine, I’m coping well’. Hugh’s protestations that he was fine were designed to prevent anyone seeing him as sick. Tracey’s decision not to share the difficulties she was experiencing was, she said, ‘her way’.

I keep a lot of things on, put a happy face on and that’s my way of dealing wae it. And I cannae change. —Tracey, age 46, (1/1)

Berta planned to ask her GP if she could be referred for some psychological support as she was struggling with her relationship, and her husband’s denial that she had cancer.

Even when I’m trying to carry on my life very well, you know, I think I need some help, you know, talking maybe. —Berta, age 50, (1/2)

#### **5.4.6 Psychological support**

Although Berta was alone in planning to seek psychological support both Clive and Danny said they thought that some type of support—Clive suggested counselling—should be made available to those with a cancer diagnosis.

Informal support was most commonly provided by partners, friends and families but there was also evidence of peer support amongst patients. Clive described a

radiotherapy waiting room where patients got to know each other, as they were there every day, and discussed issues affecting them such as travel insurance. He noted the place of humour in these exchanges between patients.

I've seen that amongst the patients, you know, the humour and the camaraderie, you know, that people with horrendous disfigurements and treatments to go through and they're laughing and joking. —Clive, age 59, (1/2)

Tracey talked about being supported by a fellow in-patient when she had become upset one night during her hospital stay.

In the hospital I did—I went to the toilet one night and I had this big rail thing wae the bag and everything on it and I happened to look in the mirror and I looked about eighty years old. My hair hadnae been washed all week, it was all standing out, my face was all red, it was all swollen. And I just crawled and I sat down in the toilet in a corner and I broke my heart, and broke my heart. And I thought 'my God, look at the state of you, you're forty-six years of age and you look about eighty'. And I just couldnae stop bubbling for hours and I think that was the break for me cause I hadnae cried except for that day I got told and I think it was just a release. And one of the old women that was in my ward she came down and said 'Oh come here' and she picked me up and gave me a cuddle and that was me—I was a wee bit better after it. —Tracey, age 46, (1/1)

## **5.5 The psychological experience of colorectal cancer one year after diagnosis**

In the intervening year between the first and second interviews participants had continued to work to make sense of their illness. Fear of recurrence emerged as the greatest psychological challenge one year after diagnosis.

### 5.5.1 Making sense of a colorectal cancer diagnosis one year after diagnosis

Participants had continued to spend time considering the cause of the illness with a range of potential causes being proposed from diet and familial links to environmental factors.

You start to think that when you hear, you know, of neighbours that are just all in this one little sort of area and the flight path going over across your house. You're sort of thinking—well, is it anything like that or is it something completely different. As I say, it could be in your food, it could be crops being sprayed with stuff that you're eating. — Muriel, age 68, (2/2)

Even one year later the experience of learning of the cancer diagnosis was recalled in detail. Both Clive and Glenda described how they had suspected, from the manner and behaviour of health professionals, a cancer diagnosis.

I knew right away, even through the stupor 'there's something not right here' because the doctor was brought in and there was a lot of mutterings in it and I kept coming in and fading out and fading in and I thought 'oh no, this isn't right'. —Clive, age 59, (2/2)

I sort of knew that that, or felt, that's what he was going to say because I saw him in the corridor and I felt, I felt as he looked at me, but maybe this is imagination, with a bit of pity or something, you know. —Glenda, age 67, (2/2)

Alice remembered diagnosis as the worst part of the experience.

I mean there's no doubt about it—that was the worst moment—when they told us that there was a mass there. —Alice, age 69, (2/2)

Making sense of their illness involved participants comparing themselves to other people with cancer. In comparing themselves to other people with cancer, participants were able to position themselves with regard to the quality of their

treatment, their likely outcome in terms of survival and their own validity as a good cancer patient.

A lot of significance can be given to the experiences of others. Glenda had gathered evidence from other patients, in the waiting room for chemotherapy, for her theory that GPs were dismissive of middle aged women's symptoms and that this delayed diagnosis.

In the hospital and—what horrified me was so many women had been like me—they had gone to their, em, GP on several occasions and had been told there was nothing to worry about. One woman went with a lump in her breast and the GP told her not to worry about it and then she went back with another one and she said the same. So, this women told me and I believe her. And another woman who had bowel cancer like me, she had gone to her GP in January and was told it was nothing. But this woman said she wanted a second opinion. She was more sensible than I was. Eventually the GP got her somewhere, but it was September before she was seen. —Glenda, age 67, (2/2)

Philippa was keen to stress her satisfaction with the manner of health professionals at diagnosis and contrasted it to a friend's experience.

She's been diagnosed with two different kinds of breast cancer. And she was speaking to the oncologist who was beastly to her and she wasn't allowed to take anybody in. Can you imagine how awful? — Philippa, age 64, (1/2)

Participants use of others' experiences to understand their own began at diagnosis. Jason assimilated the experiences of two other people, a fellow patient he met at the hospital and an ex-colleague, to mean his prognosis was terminal.

This woman says 'How long have you waited?' and I said 'Friday', you know. And she looked at me and she says 'I've waited three months for this' and I thought 'oh'. Wheels began to move quick in my mind, you know. Started to kind of panic a wee bit, you know. And eh

because I had a pal oan the railway beside me, it was another driver on the railway, had the same thing... He died, you know. I said ‘oh God, Sammy, I think I’ll be joining yae’. —Jason, age 76, (1/1)

Interpretations of others’ experiences varied. To Jason speedy treatment implied poor prognosis. For Samuel speedy treatment, as compared to others, was put down to good fortune.

You know how people will says ‘oh I’ve been waiting for this and I’ve been waiting for that’, I seem to have been fortunate that it always seems to be pretty quick for everything. —Samuel, age 81, (1/2)

Access to, and standard of, care was compared to other locations, with participants finding themselves comparing favourably to their understanding of treatment available elsewhere. Philippa used her daughter’s recent experience of care when she was seriously ill, with a non malignant complaint, to illustrate her judgement.

I think we’re luckier in Scotland than in England. I mean they did say to Samantha if it had happened to her in England she’d be dead. That was the medical people said that, ‘cause she’d have to wait too long. So I think we’re very—I do think we’re very, very lucky.  
—Philippa, age 64, (2/2)

Lorraine was clear that treatment from the cancer centre she attended was superior to treatment from other hospitals. She had spoken to a fellow patient while receiving chemotherapy as an in-patient and drawn an association between the patient’s recurrence of cancer and the patients’ treatment at a different hospital. Lorraine concluded:

People from other parts of the country, they don’t get cared for the same way as down here at (hospital) (gasp). —Lorraine, age 34, (2/2)

Overall, participants said they had had an easier time tolerating their treatment than other people.

But I suppose, really, I've come through it well when you weigh up all the pros and cons of what some people have suffered with pain and stuff. I really haven't had all that much. Just discomfort, I would say, more than anything. –Meg, age 65, (1/2)

People get worse than I get, you know what I mean. I think worse chemo. I'm no sure how that goes, you know. Maybe I had less chemo. I don't know. But I know some people were ill the whole time, you know. –Muriel, age 68, (2/2)

Learning about others' treatment could inform potential decisions about participants own treatment. Scarlett's impression of the impact chemotherapy had on her friend, whose cancer had recurred, made her think that if she experienced a recurrence she may decline chemotherapy.

She's not quite the person she was, you know. I often think about that because, I don't know. I mean, I know they would give you another course of chemo, but I'll be honest with you—I think I would ask the choices and if they said, 'Right you've got a year or whatever', I think I would live that year to be honest. –Scarlett, age 72, (1/1)

Philippa's awareness of a treatment her brother-in-law had led her to plan to ask about its appropriateness for her.

Her husband had had bowel cancer very badly but he had died a year ago. But not of that and he had lived a long time with it. And interestingly had had mistletoe injections too. That's something I want to ask my GP when I see her tomorrow. To stimulate his immune system. –Philippa, age 64, (1/2)

Much of the comparisons drawn with other patients contributed to participants theorising about the outcome of their illness, ultimately, if they would survive or die from it or from a recurrence. A range of theories were constructed. Comparisons were drawn with colorectal cancer patients and other cancer patients, with family and friends, with fellow patients, with celebrities or cancer patients profiled in the media. Participants suggested that other people's

outcomes related to them. Some said they would have similar outcomes to those whose stories they relayed. Others said their outcome would differ from the stories they were imparting.

The attitudes of others, fellow patients in the main, were evaluated by participants. There is an implied 'good patient' evident in these quotes. A good patient maintains a positive outlook, does not presume the role of 'cancer patient' beyond treatment and is stoical. By comparing themselves to others participants were able to judge themselves good patients.

A key feature of the good patient is their positive attitude. Participants imply their likeness to the positive attitudes of others.

The women in hospital are wonderful. So positive. Even the very ill ones. But I think all the time I've been there I've only met two moaners among the patients, so there you are. —Glenda, age 67, (1/2)

My Mum had breast cancer two years ago. My Mum had her breast off, so my Mum's very positive as well, so she copes well with that. —Kirsty, age 37, (1/2)

The implication from Muriel is that Mary (a neighbour) has assumed the mantle of cancer patient for too long.

Mary just keeps saying 'Well I've got cancer'. She's had it for years down the line now and she keeps saying 'I've got cancer'. —Muriel, age 68, (2/2)

Clive hints that a more stoical attitude—more stoical than that of others he has witnessed—befits a cancer patient.

A lot of the people that you meet in the waiting rooms for radiography and people are far more open about their emotions and what's happening to them. —Clive, age 59, (1/2)



Meg suspected that it was her stoical attitude, not how unwell she felt, that differed from other patients in hospital as she recovered after surgery.

One of them kept saying to me 'I don't understand how you're no in pain'. And I'm saying 'But I am in pain', you know. But I'm saying to myself 'I just maybe don't say it out the same as other people', right. And she's saying 'And do you not feel sick?'—I felt terrible. That was my worse symptom was the nauseous feeling. —Meg, age 65, (1/2)

Lorraine's fellow patients are either 'stars' or not. Stars have positive impact on their fellow patients and those who 'find it difficult' are not contributing to the experience of others.

Although it's good to be around people sometimes it can be, it just depends who it was as well, you know. I think some of them were just stars, you know. And others, well, it's not that they're not stars, but it's just that they find it difficult. —Lorraine, age 34, (2/2)

When the situation could have been worse, or is worse for other people, it's not acceptable to complain. Geoff suggests this is part of the thinking that prevents him from complaining.

My son, he works in the shipyard over there, and there's a female works in his office she's forty-two years old, went for a colostomy and all this carry on. She's got cancer of the bowel but she's also got it in her liver and her lungs. She's only forty-two and she's waiting to die. So what am I saying? I've nothing to complain about. —Geoff, age 75, (1/2)

Often participants went beyond being non-complaining and stoical to considering themselves fortunate—this, again, in relation to the experiences to others. Certain aspects of the experience, in Tracey's case having help, support her description of 'lucky'.

I've got a lot of help. I'm lucky. I'm one of the lucky ones. —Tracey, age 46, (1/1)

Yet Tracey's assertions of luck jar with the rest of her account.

I widnae wish it on anybody. —Tracey, age 46, (1/1)

### 5.5.2 Fear of recurrence

Most participants raised the issue of the possibility of cancer returning when they were interviewed for a second time.

At the time you're so busy trying to get through the treatment that's not what you're focusing on, you know, until maybe all the treatments passed and then you're feeling better and you're feeling, oh this is great, I feel good, and then you're scared to feel too happy in case it does come back. —Jacqueline, age 55, (2/2)

Fears around recurrence could be heightened at follow up appointments when participants considered the possibility of investigations revealing a recurrence.

Every time when I go in there I'm always, you know, nervous ohhhh, you know, but I try to put my mind positive, you know, even when I'm shaking inside oh oh, you know. —Berta, age 50, (2/2)

I'm coming up for my assessment again—obviously I just got the scan done there and that's worrying... The fact that you've had it is, you know, it's always at the back of your mind that it could come back again. —Andrew, age 55, (2/2)

These fears could often be triggered by pain with participants wondering whether pain might be associated with a recurrence.

Every time you get a pain you do start thinking 'oh, I hope this isn't it back'. —Jacqueline, age 55, (2/2)

It's difficult to avoid being as scared when something happens—stomach ache, or any pain, 'oh my God'. —Berta, age 50, (2/2)

It was unusual for participants not to worry about their cancer returning but occasionally they didn't. Samuel said he had not given the idea of recurrence a thought. Lorraine often mentioned feeling clear that her experience of cancer was in the past.

I just knew myself that I was better after the operation. –Lorraine, age 34, (2/2)

Changes to lifestyle had been made in order to lessen the chances of a recurrence. Jacqueline had made changes to her diet, including incorporating foods with 'anti cancer' properties. Meg avoided tiring herself.

I kind of try tae look after myself a wee bit better, you know, that's what I do. Because I used tae be the type that if I was doing something I carry on regardless. If I was exhausted I would have kept doing it tae it was finished where I don't do now. –Meg, age 65, (2/2)

Glenda said that before being diagnosed she had been very fearful of death but felt less afraid after having been around people dying while she was in hospital.

I'd always been very afraid of death but somehow in hospital people died and it didn't seem so bad, you know. Didn't seem so bad (Laughs). –Glenda, age 67, (2/2)

She went on to say that she wanted to live and had opted to do things, such as taking a language course in Berlin, which she might not have done previously.

Lorraine reflected that her first thought had been 'I could die of this', and that having to consider her own death, had, in the longer term, been a good thing.

I would say I'm glad that I've been through this, which I know people say that, but I think it's good for people to actually face their mortality as long as they survive. (Laughs) –Lorraine, age 34, (2/2)

For Lorraine considering death seems to be behind her, and Kirsty also suggests that a year past diagnosis she worries less about death. Kirsty had been worried that she would continue a pattern of cancer deaths.

But there's quite a few people have passed away, you know. And it's kind of like, but it just got to a stage there, about three people I knew, it was all cancer, and you just think 'what next, who next?', and people say 'you shouldn't think like that' you know. It was all very—kind of—it was all close to home for me for a while. —Kirsty, age 37, (2/2)

Listening to the experiences of other patients in hospital waiting rooms contributed to concerns about recurrence. Muriel hints that listening to these experiences causes her to wonder if she will be like these patients for whom 'it's no been all clear'.

And you heard some (phew) stories in there. I was going and you think you're alright but they would say 'Oh, I had that' and the next time they've went back and they've thought they were all clear and it's no been all clear. So, although you don't worry about it, it's there, you hear these things and obviously you wonder. —Muriel, age 68, (2/2)

*In the hospital a lot of women are back, you know. The cancer has come back. — Glenda, age 67, (1/2)*

Elsewhere participants make a case for the likelihood of a good outcome. One strategy was to identify differences between themselves and those with poor outcomes. Muriel's outcome would differ from that of a man she knew, who had recently died from cancer, because he had presented late (and she had presented on time).

The man I'm talking about he actually went too late, far too late. As I say it was the same thing and he died a fortnight ago so it's the right timing, isn't it? Sometimes. —Muriel, age 68, (2/2)

Clive understood his illness as different because, in contrast to others, he didn't look or feel ill.

Whereas others look really ill or looked just sick or what have you and I don't feel ill. –Clive, age 59, (1/2)

Unable to find a difference between her own experience and that of a woman whose cancer had recurred, Lorraine based her belief that she would have a better outcome on 'trust'.

But, see, hearing that it actually—because she couldn't finish her course and I was thinking about myself and I was thinking, you know, obviously I couldn't finish my course because of my bloods and all the kind of stuff but you've just got to trust that's not going to be the same story, you know. –Lorraine, age 34, (2/2)

Elsewhere Lorraine describes the efforts she makes to maintain her own belief that she will survive and she is different from fellow patients.

Afterwards I would have to get into my head 'I am not the same as these people that are in here'. And I know that sounds like as if, you know, I'm different. But none of these people that were in were in the same position as me. Everybody had secondaries. It wasn't that they had an operation and the chemo was going to get rid of it or the chemo was just doing the same job. They were all in there saying 'oh this chemo's keeping me alive for another eighteen months' and they're all like 'we know you think you're going to survive', and I'm like 'I am, I know I am' (Shouts). –Lorraine, age 34, (2/2)

Lorraine's agency is highlighted at a further encounter when she seems to actively seek out a cancer survival narrative from her Aunt.

I went round to his Mum and Dad's just to chat with them, 'cause my Aunt has had breast cancer and, you know, she was just telling me about her experience and she got surgery, she got radiotherapy and

then she got on with her life. And that was that, you know. And she's here, like, nineteen years later. —Lorraine, age 34, (1/2)

When Jacqueline had worried after likening herself to someone whose cancer had recurred ('because it's the bowel'), her daughter worked to help her understand herself as being different to them by offering her an alternative theory whereby their outcomes could differ.

Then my daughter said 'Well, maybe she hasn't been watching her diet, maybe she has been unaware that you need to be careful from now on—that you can't go on maybe the way you were living before, your very unhealthy diet or anything, she wasn't maybe trying everything.' So she was trying to reassure me with this. —Jacqueline, age 55, (2/2)

### **5.5.3 Changed identities one year after diagnosis**

One year later the participants encompassed a range of stances with regard to whether or not they were someone with cancer. A person with cancer had permanence in the minds of some who felt that they would be defined by this, to some extent, for life.

I am the same person. But I have something that says in here 'oh I am a cancer woman'. —Berta, age 50, (2/2)

In my heart I always feel I'm a cancer patient. —Glenda, age 67, (2/2)

Glenda added that a year later it was something she thought about less, and felt less defined by.

For others the year between interviews had seen a shift in their identity to a point where they were no longer someone with cancer. In the year between interviews Meg had completed a course of chemotherapy and regained her physical well being. She was no longer a cancer patient.

I don't even talk about it tae anybody and I don't and it's no because, em, for any reason, it's just it's finished as far as I'm concerned. – Meg, age 65, (2/2)

Stephanie talked about how the results from certain investigations during follow up had meaning, more meaning than assurances from health professionals, in allowing her to begin to think of herself as someone who was 'cancer free'.

They said there was no cancer there even though, as I say, as far as they were concerned, I've had all the drugs, the treatment and I was cancer free 'cause it works, you know. But I wanted the results of that scan before I was to be sure. –Stephanie, age 53, (2/2)

Philippa and Kirsty's rejection of cancer as a diagnosis that applied to them endured one year after diagnosis.

It didn't seem as if it was cancer, do you know what I mean. Just a kind of unwell feeling, but nothing too drastic. –Kirsty, age 37, (2/2)

The changes in participants' perspectives reported at the first interview were reiterated a year later. Participants had had cause to now prefer to 'live for the moment', a notion that involved doing things that may have previously been put off, for example, spending money on things that may previously have been considered indulgent.

You just have to kind of live for the moment, and life's too short and, do you know, that way and definitely it does change your perspective on things. –Kirsty, age 37, (2/2)

Before I would I've said, 'Och, no, no', you know, but now I do it. – Meg, age 65, (2/2)

I want to do things (Laughs). That's why I went to Berlin for my language course and I did enjoy it. –Glenda, age 67, (2/2)

What's the point in saving we haven't a family to leave it to, so let's just enjoy life and spend it (Laughs). –Muriel, age 68, (2/2)

As with a year previously participants talked about feeling grateful and appreciative.

You have to kind of face it and, you know, maybe just take everything for granted before this, you know, that just makes you, it gives you a wake-up call. –Stephanie, age 53, (2/2)

It's not that I wasn't thankful before but, see, every day I wake up and I say 'Oh thank you God, I've got another day with my kids' because you take it for granted. –Lorraine, age 34, (2/2)

They talked also of giving thought to what did and didn't matter and of concerning themselves less with inconsequential matters.

Look, this really brings it home to you how unimportant this is, material things are really nothing 'cause without your health you really have nothing. –Jacqueline, age 55, (2/2)

I was quite frantic at times and I was quick tae anger and issues would get my blood boiling, like, you know, things on the television or what was happening in the street and things like that. But (sigh) I've put things intae a kind of perspective now. –Andrew, age 55, (2/2)

#### **5.5.4 Psychological struggles one year after diagnosis**

As with the first interviews there were instances at the second interviews of participants struggling psychologically. However, whereas before struggles had been concerned with the diagnosis of colorectal cancer and the limitations imposed by the illness, now people struggled with other matters. Harry, for example, had lost his wife in the intervening year and described bleak periods.

I don't know—cause sometimes you get a wee bit despondent and it doesn't make much sense, you know, done it all before and don't



want to do it all again. And sometimes, when you don't feel too good, you can get down very quickly. —Harry, age 81, (2/2)

Maisie had a number of other illnesses but found her involuntarily closing eyes and painful legs meant that leaving her own house had become too difficult. She too felt despondent.

I'm glad tae get intae ma bed at night—put it that way—and that's me daen nothing, you know what I mean just? —Maisie, age 64, (2/2)

Hugh continued to live with a number of problems including his own alcohol and anger problems, an overcrowded house and difficulties managing his autistic son. He was on anti depressants; a prescription which had pre-dated the diagnosis of colorectal cancer.

Only Stephanie continued to struggle with the impact of colorectal cancer. She felt angry about the time taken to refer her to secondary care and she felt she was more emotional and more sensitive as a result of her experience.

I'm not depressed about it cause I'm just getting on with it but, you know, it was after the radiotherapy, it was—and there was a charity night that we were invited to, you know. One of these race nights or something and I just couldn't stop crying. I just could not stop crying and his brother was here and I was embarrassed cause I just couldn't stop crying for nothing. It was nothing, it was just—but I have been a bit more sensitive if you like. —Stephanie, age 53, (2/2)

There were mentions of more transient low moods, descriptions of people feeling generally well but with occasional spells of feeling despondent or depressed. Andrew mentioned that having a stoma could sometimes get him down.

I realise whit the bag means tae me, like, you know. It means I'm still here. Whenever you start feeling a wee bit depressed and things like that, you know, that's the way I look at it, you know. If it wisnae for the bag then I wouldn't be here. —Andrew, age 55, (2/2)

When participants reviewed the year that had just passed, at the second interview, they often acknowledged that coping had been difficult. Most often, from the point of view that those difficulties had largely passed.

I was with depression, not depression. It was stress, it was horrible, you know. –Berta, age 50, (2/2)

Glenda was unusual in that she talked about a longstanding history of mild depression which seemed to have lifted at some point during the year between the first and second interview. She said that when she had taken a trip abroad she had forgotten to take her anti depressants, to no ill effect, and so had not resumed taking them.

I mean, I had sort of depression for a while but—funny enough—that seems to have gone (Laughs). –Glenda, age 67, (2/2)

Ways of dealing with the psychological burden of a cancer diagnosis included choosing not to dwell on the diagnosis or choosing not to talk about the diagnosis. Sometimes choosing not to talk about the diagnosis seemed to be about opting not to deal with others' reactions.

I didn't want to tell people. It wasn't that I wanted to keep it a secret—I couldn't be bothered. I really couldn't be bothered, em, in fact I didn't tell anyone until I went in for the operation. –Glenda, age 67, (2/2)

Elsewhere, participants sought out opportunities to discuss the diagnosis, either with partners, friends and family, or with health professionals.

Clive mused over the reasons why he had not lost weight to become fit for surgery. He talked about denying the situation to himself.

Instead of, you know, sort of trying to face up to it I'm kind of running away from it. –Clive, age 59, (2/2)

This denial was in combination with a fatalistic outlook where he mused that even if he lost weight he would learn he would die. This notion was at odds with his own reports of health professionals telling him that his tumour was contained and had shrunk in response to chemotherapy and radiotherapy.

I sort of say to myself, you know, 'You go on a diet and sure as fate you'll get a diagnosis that you're going to die in a few weeks anyway or a few months or whatever'. So, you know, those kind of conflicts. And so you end up taking the easy road which, of course, is what people like me do anyway with weight. —Clive, age 59, (2/2)

As had been the case a year previously participants had found their greatest psychological support in their partners, friends and families.

I've got a good family round about me they're all the psychology I need, like, you know. They don't allow you tae get selfed on yourself, you know, they're aye giving you a wee buck tae smarten your ideas up. —Andrew, age 55, (2/2)

## **5.6 The social experience of colorectal cancer at diagnosis**

Participants described how the physical and psychological effects of colorectal cancer impacted the social dimensions of their lives. The effect of colorectal cancer on participants' finances, employment, domestic work, socialising and holidays are outlined in this section.

### **5.6.1 Finances at diagnosis**

A number of participants, particularly those who were retired, said that their illness had not impacted them financially: their income remained the same and there had been no, or minimal, costs involved.

However, those who worked experienced protracted absences from work which usually resulted in a significant reduction in income, either from the outset or at the end of a sick pay entitlement period.

Tracey's income was greatly reduced soon after her diagnosis because, although her employers continued to pay her, she was paid only for her contracted 20 hours and Tracey had routinely worked overtime. As a result she was struggling to meet her basic costs. Tracey wondered how she would be able to meet her living costs when her pay was reduced from full pay to half pay after six months of absence.

I'll get half pay, I don't know what happens with my rent, I don't know what happens with my council, I don't know what happens with anything really I would need to cross that when I came to it. –Tracey, age 46, (1/1)

Six months of full pay was standard for those employed by government agencies or large businesses and this worried those undergoing chemotherapy or with chemotherapy planned. They would be unable to return to work within six months as chemotherapy courses routinely lasted six months and this was in addition to the time taken for diagnostic tests and surgery.

Stephanie and Berta expressed concerns about managing when their incomes decreased after six months but in both cases their husbands were in a position to support them. Danny, who was self employed, also relied on financial support from his partner when his income stopped as soon as he became too unwell to work.

My partner works full-time. I think if it hadn't been for that, it would be a big problem. But obviously, anything like this, any hiccups, you know, we have no savings at all really so there's nothing there to fall back on. And that's not through lack of foresight—that's lack of money—that we don't have savings. –Danny, age 51, (1/1)

Andrew was unusual in that his company planned to pay him for the duration of his absence which included a chemotherapy course. He believed that financial worries could impair peoples' recovery.

They continue to pay me even though I'm off and I think that is—that's a big relief that you don't have the financial worries. I think if I

had financial problems and the operation, then I think it might have been a different story. I think it would have affected how you cope with the operation, how you cope with the aftermath of the operation and I think in some cases it might actually force people back to work sooner than they should be. –Andrew, age 55, (1/2)

Although retired participants did not face a reduction in income some had concerns about potential costs associated with their illnesses. Costs associated with the illness were most usually the cost of transport to hospital appointments, which could be frequent during the diagnostic and adjuvant treatment phases. Elsewhere people needed new clothes because they had lost weight and their clothes no longer fitted.

Uncertainty about entitlement to benefits now and in the future was described. Doris did not know if she was expected to pay for the social care she was receiving. Harry wondered how he would meet the cost of residential care for his wife if it transpired that he was unable to care for her at home. Harry commented that he would have appreciated very much having his entitlement to benefits explained.

Applications for benefits to meet the increased costs or to cope with reduced income had been made by a number of participants. When people were successful in obtaining benefits they felt relieved of financial worries and able to facilitate their recovery by employing help at home and having the opportunity to rest. Occasionally participants were surprised at receiving benefits as they weren't enduring financial hardship.

Now I have been awarded that so that was a little surprise getting that, so I've had help, I've had financial help not that, you know, I was like really, really needing it—I don't mean I was like, but it was nice for to do that, it was appreciated getting that. –Jacqueline, age 55, (1/2)

Applications were not always successful and in these instances people were hurt and frustrated and felt that their description of their situation hadn't been believed or taken seriously enough. Geoff described a convoluted series of

events including an assessment by a doctor, a rejection of their initial claim, an appeal and second rejection. These events had caused great anguish and Geoff and his wife listed the extra costs, mainly taxis, they were paying for as well describing the extent of Geoff's incapacity. Additionally, they had found the assessment by the doctor humiliating.

I laid it out on the line, I didn't make anything up and the Doctor said in his opinion he didn't need it because he could wash himself. Well, he couldn't. –Geoff 1/1 (wife)

In spite of feeling that the rejection of their claim was unjust Geoff and his wife had decided not to pursue their claim any further. Maisie, too, was not going to pursue a rejected claim even though she was struggling to pay for taxi fares to appointments.

They jist wrote back and said that I didnae qualify for it or something and I just left it. –Maisie, age 64, (2/2)

Support from charities in the form of grants or advice about applying for benefits and grants had been received in just a couple of cases. Hugh had been visited by a Macmillan benefits advisor to assess whether he was receiving benefits he was entitled too. Tracey had received a grant from Macmillan after her GP had completed a form.

She had put down my costs my incomings, my outgoings and said I was left with twenty-five pounds a week and that's absolutely ridiculous. They sent me through three hundred and fifty pounds, that was absolutely wonderful, two hundred pounds for heating and a hundred pounds towards bus fares. –Tracey, age 46, (1/1)

Savings were used by some to meet increased costs or to meet routine costs on a reduced income. Geoff commented that he was not in a position to replenish his savings because he was retired. Offers of financial help from family members had been made to some of those experiencing hardship and there was reluctant recognition that these offers may have to be accepted in the future.

### 5.6.2 Employment at diagnosis

Returning to work posed problems for some as they endeavoured to deal with physical issues such as digestive dysfunction and fatigue away from home. Fatigue meant that working participants were unable to work for the length of time they had previously worked.

My sort of energy levels are low, so I don't feel able to concentrate on much for too long. So instead of trying to do too much, I've luckily been able to cut down to a level that suits me and days which suit me... probably at the moment I'd say I'm down to about a quarter of what I was doing previously. —Danny, age 51, (1/1)

Employers were described as sympathetic and accommodating when participants had needed time off for investigations or treatment or when participants had felt unwell.

My work's been very, very good, you know, working around Doctor's appointments and waiting for Doctor's appointments and they must be sick to death. —Stephanie, age 53, (1/2)

Some participants were required to attend meetings and reviews with employers but these were never reported as problematic.

I went to see my GP and he gave me my Doctors Certificate for a month and after that—I think I have an interview with BUPA, I think. —Berta, age 50, (1/2)

Employers had supported participants' suggestions that when they did return to work it would be to lighter work, fewer hours, working from home or a phased return.

The biggest problem for those that worked was that they missed working, they missed their colleagues and they missed being busy.

I'm just used to working—that's another thing—I like my job. —Kirsty, age 37, (1/2)

If I have to stop working altogether, I'd go insane because, em, I can't just sit about and do nothing. –Danny, age 51, (1/1)

I'm missing my work and all my colleagues—I really, really am that's the drawback about it. People go 'enjoy it' but no, it's no for me. – Tracey, age 46, (1/1)

I said I need to work because it makes me feel alive, yeah, any kind of job I will feel alive, you know, working, working. –Berta, age 50, (1/2)

Too many doctors have said to me 'There's more to life than work' and here's me thinking all I want to do is get back, you know. – Stephanie, age 53, (1/2)

Stephanie's quote hints at work as central to 'normal' life which she is unable to participate in because of her illness. Something Andrew states more expressly as he describes his plan for an overall recovery and sets as his first target a return to work. He goes on to mention that the idea of target setting is borrowed from project management courses he has attended.

Well I think my first target is actually to get back to work... My target as regards work is end October, beginning November I want to be back in there at least a couple of days a week, at least a couple of days a week and build up from there. –Andrew, age 55, (1/2)

Lorraine found the news that she would need to remain in the UK for three years for her treatment and follow-up very shocking as it meant that she and her husband would be unable to resume their work abroad. She hoped to be able to continue that work eventually but in the meantime needed to very quickly make a plan for her and her family for the next few years.



### 5.6.3 Domestic work at diagnosis

Domestic work which is often physically demanding was beyond the capabilities of participants when they were interviewed initially, often in the weeks following surgery or during adjuvant treatment.

See even making my bed—when I'm making my own bed—I have to go and sit down I'm tired, you know, that's the weakness that I feel. Ironing—I iron and I've to go and sit down and then get up and do another wee bit and sit down again. —Doris, age 84, (1/2)

Spouses or partners sometimes took on extra domestic chores.

In fact for the first couple of weeks he did most of the cooking, well, it was his version of cooking and I was on this absolutely bland diet. —Teresa, age 70, (2/2)

Relying on partners could be problematic if the partners were not physically fit. Maisie describes the increase in work for her partner taking its toll.

Aye, he gets the shopping in an all and he's no very well either—it's a shame. Ah he's shattered—he's lost weight, he's lost about a stone. —Maisie, age 64, (1/2)

A sense of guilt at increasing a burden on others was sometimes evident, as was a sense of frustration at not being able to carry out routine domestic tasks.

I find that it takes a lot out of me and leaves me very weak and I'm not doing my sort of normal household chores as quickly and I'm an impatient person anyway, I think, because I've always been able to do things. —Muriel, age 68, (1/2)

Sometimes participants said the domestic chores simply did not get done, or were done to less exacting than usual standards. In a couple of cases participants were able to pay for someone to help them at home. Glenda had started to use the internet to do her shopping and was using ready meals to avoid cooking. Kirsty was getting help from her school-age children. Scarlett

cooked meals and froze them so that when she was feeling unwell after a cycle of chemotherapy she did not have to cook.

In the same way that participants were keen to resume their paid employment they were also keen to resume their domestic work.

I would like to wash it and that but I don't want to lift a bucket of water in case I do myself damage. –Charlie, age 72, (1/2)

#### **5.6.4 Caring for others at diagnosis**

Those with caring responsibilities themselves found their inability to carry out their caring duties, and having to find support from elsewhere, distressing. Harry's wife was being cared for in a residential setting during Harry's hospital stay and recovery. Harry was keen to have his wife at home again as she was losing weight and he did not like to think of his wife in a care home environment.

The whole idea of old people just wandering aimlessly. There was a wee man come in with a cup and he comes back in five minutes with the cup and he's back in another five minutes with the cup. A wee woman sitting clapping her hands and you say, what quality is this? – Harry, age 81, (1/2)

Jacqueline's elderly mother received residential care for three weeks over Jacqueline's hospital stay but Jacqueline had concerns over how she would manage to care for her mother during the adjuvant treatment phase.

#### **5.6.5 Social Care at diagnosis**

There were instances of elderly interviewees requiring social care to support them at home after their discharge from hospital. The care had been arranged while they were in hospital and in place on their return home. Participants were happy with their care which involved carers coming in two or three times a day to organise meals and do light housework. Doris needed help with bathing and dressing and her carers also carried out basic housework tasks and did occasional

bits of shopping for her. Before her surgery she had been independent and hoped to require less help in the future.

If I get stronger I might not need them—I might just not have them.  
But I've been so glad of them coming in and it's made such a  
difference knowing that somebody's there and they're so kind. —  
Doris, age 84, (1/1)

Jacqueline had received social care to help her as she cared for her elderly mother. Again the care had been arranged when she had been in hospital but when she returned home she found she was able to manage and stopped the care. When she let a social worker know that she had stopped the care the social worker was concerned that it may be difficult to start again should she need it during her chemotherapy. At the time of the interview the care package had been reinstated but Jacqueline turned the carers away every day when they arrived. Jacqueline worried that she may face a significant bill for the care.

Some participants refused offers of social care with protestations of independence and claims that social carers were of little help. Those who thought social carers wouldn't be helpful believed they didn't have enough time to be useful and one participant's husband thought they were untrustworthy and talked about people. One elderly couple had previously had social care but hadn't found it useful so they had refused the offer of help made.

Another one that would come in and she would sit down and she would say 'Oh, I'm knackered I've walked fae so and so place. Oh, I'm no worth a button, what are you wanting done?'—Samuel, age 81,  
(1/2)

### **5.6.6 Social lives at diagnosis**

The ability to socialise was compromised for many participants. Tiredness and digestive dysfunction could get in the way of social pursuits but the interviews contained evidence of effort to resume social lives and pastimes relatively soon after surgery.

Alterations to diet meant that some people were unable to enjoy eating socially as much as they had previously although some participants accommodated their altered eating habits in a social situation by eating and drinking less than they would have previously.

Danny described a social (and work) life very much centred around food and wine.

I suppose I would previously eat—socialising a lot more and having lunches out and things like that which I don't do now because I just find that uncomfortable and eating large meals is just not a good situation because that just gives you, you know, loads of gas and pain and it's not good. So, small meals and small bits and pieces here and there is good for me at the moment and not having a glass of wine is absolutely criminal but I just don't think it's agreeing with me at the moment and I am trying but it's not agreeing with me and that's fine. Perhaps when you meet people, you know, to discuss work or even socially it's over a few glasses of wine previously but I just won't do that now. —Danny, age 51, (1/1)

Harry had enjoyed a beer with a friend but there had been repercussions with his stoma bag.

My pal decided to come down and watch the football and he brought four wee cans of beer, you know, just wee things. Well, I was sitting there enjoying this beer and it filled my bag about three times with the gas, so I had to say don't bring any more—I can't take it and I was quite enjoying it as well, a wee half pint. —Harry, age 81, (2/2)

Hugh found playing darts too exhausting and did not want to cope with his faecal urgency away from home. Sometimes participants were not keen to have conversations with people as their cancer diagnosis could prove a difficult topic to address and avoiding talking about their illness could be equally awkward. Treatment regimes could disrupt social regimes. Clive was unable to paint, as he had been used to doing every day, when he was required to attend hospital for radiotherapy daily.

I love to paint in the afternoon—it's the best light, well, the best light for me and of course that's every afternoon—I haven't been able to paint this summer at all. —Clive, age 59, (1/2)

However Andrew's treatment timetable was altered to allow him to attend his daughter's wedding.

So they agreed to re-schedule the surgery for after my daughter's wedding, which was great, you know, it was a big bonus for us to get that. —Andrew, age 55, (1/2)

Friends and relatives had sometimes accommodated participants' limited ability or inclination to socialise and visited them at home. Alice was unusual in that she had already resumed her social pursuits and been at her dancing class, at bingo and walking her dogs. Others voiced hopes that they would be able to resume their social lives in the months ahead.

Managing to leave home for relatively short periods of time to do everyday tasks, such as shopping or attending appointments, could be difficult in the weeks following surgery. Following the advice of doctors not to drive for six weeks post surgery proved limiting, especially where the participant was the only driver in the household. Scarlett, who was feeling unwell because of chemotherapy, had decided herself that she was not well enough to drive.

I mean, I wouldn't drive—I just don't think I should be driving so I don't feel I'm in total control of anything, you know, so that limits me as well. —Scarlett, age 72, (1/1)

Those suffering from digestive dysfunction dreaded 'accidents' away from home, and some had experienced fecal incontinence in public places. Hugh found these episodes excruciating and choose to stay at home.

I'm feart cause it's happened, you know. And it's, know, that your bowel just moves and it goes doon the leg and right oan tae a flair and it stinks tae high heaven. You know whit I mean? And it's embarrassing

so I'm not going out. I'm not going out and it's as simple as that until that bit is settled doon. —Hugh, age 48, (1/2)

Those with stomas became familiar with where they could access toilets suitable for changing their stoma bag.

They've all got toilets and the likes of some of the big stores—they've got the disabled toilet and that's good—I just go in there because there's more room if you need to change the bag and things like that. —Teresa, age 70, (1/2)

Figuring out when a stoma bag would need changed and working around that timing meant that Teresa could plan to be away from home for longer periods of time.

In the morning—maybe it's because I'm on my feet—it works, it does work but after about a couple of hours you're up and you've had your breakfast, it sort of calms down a bit. So, I'll have to be up early on Monday morning so by the time I get to the bus station I'll go into the toilet at the bus station and I'll be alright until the next stop or to lunch time. —Teresa, age 70, (1/2)

Others felt that at this point, just weeks after surgery, they had not regained their health to the point that enabled them to resume everyday errands away from home. Meg mentioned that she lacked confidence shopping.

Although I'm going to the shops, that was the wee bit I noticed, that I didnae really have the confidence to walk about myself because I can walk for hours in the shops, you know, do this, that and the next thing. But I noticed I was a wee bit hanging back. —Meg, age 65, (1/2)

Doris wasn't able to use buses as the step up onto the bus had was now too high for her. She used taxis, although some of them had a high step too, and she no longer went shopping alone.

I go down to the shops but somebody takes me—I'm either in a car or a taxi and I'm with someone, you know, my home help will come down with me. But I've never been on my own going down to the shops. —Doris, age 84, (1/2)

In some cases comorbidities proved very limiting. Samuel's breathlessness made walking short distances, for example, the walk from the hospital car park to the clinic, difficult. Maisie was housebound because of the arthritic pain in her legs and the involuntary closing of her eyes.

### **5.6.7 Eating at diagnosis**

Eating was a feature of social lives and also a feature of day to day living. While some participants made changes to their diet to avoid pain and discomfort (see section 5.2.3) others had switched to a healthier diet in general or to a diet which included foods which they believed helped prevent cancer.

Now I'm really positive about my diet, I mean, I'm very careful now and I was eating a lot of chocolate—I know that I probably wasn't on the right diet. Now I'm, like, taking brazil nuts, apples, my bran every day. I've cut right back on the chocolate. I have only have a tiny bit, if I have the craving. A little dark chocolate and I've cut right back on that and I just feel I'm doing everything to try and, you know, be healthier and try, if it's anything to do with that. I don't know. — Jacqueline, age 55, (1/2)

Try not to eat red meat because probably it's the one that it says is not good when you have cancer and things like that. —Berta, age 50, (1/2)

Tracey had increased her intake of fruit and vegetables in an effort to improve her health but elsewhere participants did not see any need to make changes to their diet.

I don't take all this rubbish five times a day and all that. I mean, I've never done that in my life. Never ever bothered. But my diets no

changed, you know. The diet I get is the same diet the wife has always gave me. –Samuel, age 81, (1/2)

### 5.6.8 Holidays at diagnosis

Holidays were mentioned frequently in terms of bookings having been cancelled and plans postponed to accommodate treatment schedules. Most participants were philosophical about having to alter their plans and said that they looked forward to being able to take a holiday after treatment, often to mark or celebrate the end of treatment. Plans for future holidays remained loose as there was uncertainty around treatment schedules and the amount of time that recovery would take.

I mean there's no way I can organise a summer holiday or anything like that because, well, I could go in next week and if the blood count's not right they can't do it so that knocks it back a week. –Scarlett, age 72, (1/1)

Some participants noted the impact their colorectal cancer had on their partners and looked forward to a holiday for their partners' sake. Danny, for whom the cost of travel insurance had proved prohibitive, was frustrated at not being able to take a holiday because he felt that his partner needed a break.

Participants described difficulties obtaining holiday insurance.

I tried to get away on holiday and do a bit of business, actually, in Spain, shortly before my chemo started, 'cause I thought I might be absolutely washed out for months and it would be nice to get a break and had been warned that travel insurance would be a slight problem. –Danny, age 51, (1/1)

Some had been directed to cancer charity web sites for information about companies that may be sympathetic to cancer patients or directly to particular companies by the specialist nurses. Other participants wondered how to proceed or simply assumed insurance would be prohibitively expensive.



The other main bone of contention was the fact that you can't eh get insured, the risk and everything. —Clive, age 59, (1/2)

Those who did attempt to obtain travel insurance reported expensive quotes and a great variation of prices quoted. Travel insurance proved to be prohibitively expensive for Danny and he was therefore unable to take the break he had hoped to.

The cheapest quote I could get for a week was in Spain was £500 and from another company, which I was advised to check out—they quoted me £2,060 for a week and that really made my mind up not to bother going anywhere, that's before any travel or any costs on top. —Danny, age 51, (1/1)

There were other issues obtaining travel insurance. One enquiry which Danny made about cover had to be made to a 'premium line' number at significant expense to him.

I spoke to a few of them about trying to get quotes for travel which was a very lengthy process on the phone but you're unable to do it any other way—they don't seem to have any offices—certainly in Glasgow anyway. So it's telephone only and unfortunately what really annoyed me was that a lot of them are premium rate lines which I think is completely wrong. —Danny, age 51, (1/1)

Danny was not receiving curative treatment and was unhappy about being asked, on the phone, about his prognosis. He was also unhappy that his consultant would be asked to complete a questionnaire.

They also wanted my consultant to fill out a questionnaire so I thought, you know, this is just complete and utter nonsense and I can see why many people over the age of 60 who cannot get travel insurance for under that price because they have some problem or other, even high blood pressure, they just go without insurance at all. —Danny, age 51, (1/1)

Danny brought up the idea of travelling without insurance and said that that had been tempting. He did however understand that insurance companies justified these high premiums when there was a risk that a nurse could be required to accompany a patient back to the UK. As Danny had an open wound he said this was a real possibility but nonetheless felt it was unjust and compared his risk to that of people who drink to excess on holiday, with the associated risks, yet enjoy cheap insurance.

Others who had undergone surgery and were beginning to feel well did not understand how expensive insurance could be justified. They felt that colorectal cancer was not an illness that would lead to a sudden deterioration or require medical assistance before they would have time to get home.

I mean, financially, if we had gone on holiday I could have got insurance but it would have cost me an arm and a leg—I never knew that. I don't see how I'm a threat to anybody. —Stephanie, age 53, (1/2)

Cover which excluded any cancer related cover was mentioned by Clive when he relayed a conversation about travel insurance which had taken place with a group of cancer patients in the waiting room for radiotherapy the previous day.

They said something strange—you can't get insured for that which I took to mean the cancer but you can get insured for everything else, if that's what they meant, you know, that they sort of ring fence you. So, I don't know if that's what they meant—so I assumed that's what they meant. —Clive, age 59, (1/2)

Similarly Philippa said that she was able to travel with her annual travel policy, which excluded cover for cancer.

I have full insurance apart from anything related to bowel cancer. — Philippa, age 64, (1/2)

## 5.7 The social experience of colorectal cancer one year after diagnosis

Most participants had recovered well by the second year, describing a return to more normal life, including work, travel and holidays.

### 5.7.1 Finances one year after diagnosis

Financial issues were an issue for a number of participants one year after diagnosis, especially the experience of applying for benefits and the challenges of the benefits system. The challenges of the benefits system were described by Stephanie after she had applied for money when her sick pay entitlement expired and she was receiving pensionable pay of just £249 a month from her employers. She thought that completing the form for Disability Living Allowance was too taxing for people who are unwell.

You shouldn't have to go through that though, Susan, honest to God, it's like a big book. I mean you're not well, you know, you just can't face all that I just couldn't face it. —Stephanie, age 53, (2/2)

Stephanie had received a grant of £500 from a Civil Service Benevolent Fund and £10 a week from her employment union but was keen to stress that she had only found out about that these, and other sources of money, by chance.

Well, into the treatment somebody mentions like a Macmillan grant— 'Oh what's that then?' They don't, nobody's falling over themselves to help you out with a bit of money. I didn't know about that and, like, the Disability Living Allowance—that was months into my treatment before somebody said 'You might qualify for that'. —Stephanie, age 53, (2/2)

Not everyone was happy with the notion of applying for benefits. Some did not want to be labelled as having a disability, as they expected to be cured. They refused to apply for benefits in spite of suffering financial hardship as they felt the application would represent them taking on a 'sick' label: something they wanted to resist. Lorraine filled out a form to receive benefits but was pleased

when the form was lost in the post as she wanted to think of herself as healthy, in spite of having to manage on a very meagre budget.

This is money for somebody who is going to have severe problems or is going to die basically. I don't want that money. –Lorraine, age 34, (2/2)

Andrew had been advised to make an application for benefits but he said that would not as there were people in greater need than him.

I would feel a bit awkward if I was actually taking any kind of financial assistance thinking it might be keeping it back from somebody that did need it. –Andrew, age 55, (2/2)

Those who experienced difficulties accessing benefits thought a cancer diagnosis should enable easier access to benefits and indeed some people had indeed enjoyed ease in accessing benefits.

I contacted Social Services and they gave me money. Yeah, I was absolutely stunned and they were so nice. –Glenda, age 67, (2/2)

Those who had successful benefits applications had been able to afford services that went some way to compensating for their physical incapacity. Glenda employed a cleaner and Doris was able to take taxis.

Oh, much better off, I'll tell you that—better off than I was when my husband was living—so there you are. Well, normally I would have never took taxis, you know, when I was able, just you didn't do these things—I'm not taxi minded but I have become that way now because I know I can't get off and on the buses the same. –Doris, age 84, (2/2)

Occasionally employers continued to pay full pay beyond six months. Andrew's employers had continued to pay him full pay during his illness and phased return to work. Lorraine and her husband had been working abroad, for their church, when she had become ill. Her employers had continued to support the family when they returned home for Lorraine to receive treatment, and this small

income was occasionally boosted by gifts of money from family and individual church members.

Although Kirsty's pay had been reduced at six months, her case was unusual in that her colorectal cancer led to a marked increase in her income. This drop in income was offset by a successful claim for Disability Living Allowance and, in addition, she had critical illness cover with her mortgage which paid the outstanding amount of her mortgage shortly after she received her diagnosis.

The only cost associated with colorectal cancer which arose after the initial interviews with Andrew was the significant cost of dental treatment that he had had to pay.

### **5.7.2 Employment one year after diagnosis**

One year later the majority of participants who had been working had returned to work and described being well-supported in their return. Often their return had been phased with a gradual build-up of hours worked. Kirsty described a very gradual return where, over a few months, she built up from two mornings a week doing paperwork to full-time work involving more physical tasks. Berta, who worked for the local authority in a catering post, was moved permanently so that her duties would be less physically demanding. Stephanie's employers suggested that she take longer to build up to her hours on her return than was usual company protocol and they accommodated her request for permanently reduced hours.

Participants were pleased to have returned to work, noting the centrality of work to 'normal' life.

I just wanted to get back to my work, really. —Kirsty, age 37, (2/2)

I felt I was really ready to go back to work—I wanted to get my life back, be back where I was, you know. —Stephanie, age 53, (2/2)

However managing ongoing physical problems in a work context could be difficult. Returning to work could exacerbate fatigue and carrying out physically

demanding tasks or concentrating proved hard. Digestive dysfunction, specifically the need to access a toilet at very short notice in a more public environment, had also caused worry.

In the twelve months between the first and second interview Lorraine had not undertaken any paid work and had cared for her young children. She still had plans to work abroad again in the future but, by the second interview, was immersed in more immediate plans for her and her husband's work and career in the UK. Lorraine was planning to return to work part-time and had re-registered her professional qualification, which had lapsed when she had been working abroad, before looking for work. Her husband was working for the church and had agreed to continue to do so for a least a further 18 months.

### **5.7.3 Domestic work one year after diagnosis**

A year later most participants had been able to resume their usual domestic chores.

I would say I'm back to being able to, you know, do everything without thinking twice about it now. —Muriel, age 68, (2/2)

Sometimes they talked about being slightly less diligent in order to accommodate feeling less physically fit. Most spousal relationships had resumed their previous arrangements regarding division of domestic labour with some exceptions. In a couple of instances a female participants' inability to carry out her usual work at home had highlighted to a male partner the extent of the work done and this, in turn, had led to a more equal division of labour.

He's like 'I can't believe I just let you do all that housework' and he was like 'You worked full-time and I worked full-time and then you came and did all the cooking and all the housework'. Like, you wouldn't consider that now cause he's, like, so involved—I mean it really is—it's like half and half, really—I mean I probably cook a wee bit more than he does but he probably does more dishes. —Lorraine, age 34, (2/2)

Adult children had provided support with cleaning, cooking and shopping in the months between the first and second interview.

#### **5.7.4 Caring for others one year after diagnosis**

Although participants' physical well-being was improved one year later, their ongoing physical issues combined with personal circumstances could conspire to make caring responsibilities very difficult. Samuel needed more help from his adult children with his wife, especially managing her frequent visits to hospital, as he did not have the strength to assist her walking. Hugh's teenage daughter had recently had a baby and she, the baby and her partner were living with Hugh and his wife and autistic son. Hugh's son was not coping well with the baby in the house and as a result Hugh and his wife were struggling to care for their son. In addition to looking after her children Lorraine was spending a lot of time with her brother who had recently had a trampolining accident resulting in a spinal injury. Jacqueline continued to care for her mother whose behaviour was becoming increasingly difficult to manage.

Sometimes my Mum can have mood swings with the stroke—that can be a bit, emotionally, that can be a little bit difficult. She can have depression and that can pull you really down. But she refused to take her pills—absolutely refused to take her pills. —Jacqueline, age 55, (2/2)

At the second interview social care arrangements were continuing to work well for Doris. Doris appreciated the help with cooking, cleaning and her personal care and very much enjoyed the carers' company.

Champion. They're really very good I have one morning—one for breakfast, one for lunch and another one for teatime and each one's nice—oh, they're really awful nice—get on great—I says 'You're just like friends now coming in, popping in instead of carers.'—Doris, age 84, (2/2)

Elsewhere the service offered had not met the needs of participants. Harry found the timing of visits, the purpose of which was to organise meals for him,

didn't suit him. Often the carer who was scheduled to make his breakfast didn't arrive until 11 am and someone would arrive to prepare an evening meal at 4.30pm. He regularly turned the service away and eventually it was withdrawn. Jacqueline found explaining her mother's needs to social carers onerous:

I just found it more of a strain all these different people coming in and they were all lovely but I was having to explain 'this is how you work an artificial limb' and it was actually getting me more uptight having to, you know, I found it easier just to do it myself. —

Jacqueline, age 55, (2/2)

### **5.7.5 Social lives one year after diagnosis**

Social lives had largely returned to normal by the second year. Participants were enjoying feeling well enough to be able to resume activities they had previously enjoyed and in some cases had embarked on new interests.

Well, I've joined, that's me joined a fitness, I go, I've been going four times a week. —Meg, age 65, (2/2)

Social occasions were described as key moments for participants to appreciate successful treatment. Stephanie's family postponed Christmas until her adjuvant treatment ended in January and celebrated her treatment ending.

We went to Liverpool and had the Christmas at my mum's with the family. So we cooked a dinner for twelve. Well, my sister and that were all there, you know. I didn't really do very much but, yeah, so it was just a big celebration, you know. It's Christmas. My mother kept her tree up and everything. —Stephanie, age 53, (2/2)

However, coping with ongoing physical issues in a social context continued to be problematic. Dealing with faecal urgency and incontinence was difficult away from home. Hugh preferred to stay at home because of his incontinence but elsewhere imaginative strategies had been employed. Philippa wore children's large pull-up nappies and carried a sari with her so that she could wrap it around her in the event of an accident. Participants were very familiar with the



whereabouts and quality of toilets that were available to the public. Some commented on what they felt was the outrageous decrease in availability of local authority public toilets. Glenda struggled with fatigue in social situations and had been too tired to enjoy a wedding she had attended. She slept a lot and had missed church due to oversleeping.

In fact, on Sunday I really wanted to go to church, so I set my alarm and the alarm rang and it's on snooze, it went off then it rang again and, I mean, I heard it, and I had the radio on full pelt but I just somehow couldn't get up and I just fell right back to sleep again. — Glenda, age 67, (2/2)

### **5.7.6 Eating one year after diagnosis**

Altered diets were described when participants were interviewed after a year. By this point diets were well established with participants feeling confident about what they could and couldn't eat in terms of certain foods, for example, a number of participants avoided spicy foods and high fibre food.

I just try not to eat a lot of spicy things and, you know. I try to be careful with my diet so that—not to take things that I think is going to upset me. —Muriel, age 68, (2/2)

Some listed specific foods which they knew their digestive systems no longer coped well with, for example, Alice avoided nuts and onions.

Changes had also been made to portion sizes as participants were no longer able to comfortably digest large meals. They also reported changes to alcohol habits having developed a reduced tolerance to alcohol.

I do know that if I overeat and I over drink than I will suffer for it 'cause my tummy just doesn't like me to do that, you know. Whereas before I could have a good swally. —Stephanie, age 53, (2/2)

Given the centrality of eating and drinking to socialising many participants found that their issues around eating impacted on their social life.

### 5.7.7 Travel and mobility one year after diagnosis

Treatment and illness compromised participants' independence and when they reflected on the time since their initial interviews participants noted significant support from partners and spouses in enabling them to leave home for routine tasks such as shopping or to attend hospital appointments. Sometimes spouses took leave or worked flexible hours in order to drive the participants to daily appointments for adjuvant treatment for periods of five or six weeks. The degree of support required from spouses, and the disruption it caused to their lives, particularly their working lives, caused unease for participants. Jacqueline offered to take hospital transport to her daily appointments but her brother stepped in when her husband was no longer able to drive her. Stephanie said her husband's employers had been supportive and allowed him to drive her to appointments but she eventually switched to using transport provided by the hospital.

I used the driver at that point 'cause, I mean, (husband) has taken me on every appointment but he couldn't physically do that every day for five weeks—he just couldn't do it. His work have been brilliant—absolutely great—but he couldn't do it, like, forever, it's not fair. — Stephanie, age 53, (2/2)

By the second interview however most participants were able to leave home and travel with ease. Drivers were able to drive again and had been enjoying the independence and freedom that driving afforded them. Those who had ongoing digestive dysfunction talked of accidents that had occurred in the intervening year between interviews. In the same way that they had found strategies to allow them to socialise participants found ways of managing that allowed them to be away from home and to travel. Muriel carried a change of clothes with her and Philippa took anti diarrhoea tablets for longer journeys. They claimed that the potential for accidents would never dissuade them doing what they wanted to do. Similarly those with stomas said they had had some accidents but were becoming increasingly confident managing their stoma while traveling and away from home. Hugh, however, described himself as incontinent and said that he was still not prepared to leave home because of the potential for embarrassment.

Those who were confined to their homes or experiencing difficulty getting out were limited by their comorbidities rather than colorectal cancer. Clive and James both suffered from breathlessness which made walking short distances difficult. Both men struggled with the walks involved in attending hospital appointments.

I mean, I can't park in the car park and walk to where the clinic is—I mean it's just beyond me. Well, it's not miles, but it could as well be.  
—Clive, age 59, (2/2)

Sort of losing my breath, I cannae walk very far, you know what I mean. If I go to the hospital and if I've got to park in the car park and then walk fae there up to the ward, I'm wheezing. —James (2/2)

Maisie's arthritic pain in her legs and eye problems meant that she remained housebound. Her very occasional outings were recalled as being extremely uncomfortable and embarrassing and so Maisie choose not to leave her home.

### **5.7.8 Holidays one year after diagnosis**

As had been anticipated at the first interviews participants had taken holidays to mark the completion of their treatment. Often people had taken more holidays than was usual for them, or had travelled further or taken longer. Some issues with digestive dysfunction and managing stoma bags on holiday were described. Berta, who travelled to Peru to see her family said the flight made her feel 'gassy', and Teresa said that an oily diet in Yugoslavia had impacted her bowel function. Andrew described difficulties finding a hygienic environment to change his stoma bag in some places he visited during a Mediterranean cruise. Teresa was concerned that her stoma bag would leak while she was staying in a hotel.

I was just careful—I was worried about, you know, in case it would leak in the bed but I had a towel or something under me and I managed quite well. —Teresa, age 70, (2/2)

Maisie said she was not well enough to take a holiday but it was her comorbidities, her problems with her eyes and legs, that were limiting her rather than any ongoing issues associated with colorectal cancer.

We used tae go tae Redcar, you know what I mean, in the summer for a week or two but eh I couldnae manage, definitely no. —Maisie, age 64, (2/2)

Travel insurance was no longer a talking point one year later. When prompted participants mentioned that they had found affordable insurance and they sometimes mentioned it excluded cancer. Participants believed that getting ‘the all clear’ allowed them to get insurance. Stephanie had travel insurance included in her husband’s bank account and Stephanie’s husband had telephoned the insurers to let them know about Stephanie’s colorectal cancer.

There was no extra charge because I’ve got the all clear ’cause I’ve had the treatment. —Stephanie, age 53, (2/2)

Muriel was waiting for her next follow up appointment before going ahead with plans for a trip to Canada

I would like to know I’m all clear especially with something like that because you also need to have insurance and I know that can be quite difficult. —Muriel, age 68, (2/2)

More unusually Andrew did describe some difficulty obtaining reasonably priced travel insurance. He researched potentially affordable companies using the CancerBackup web site<sup>14</sup> but was given expensive quotes.

A lot of difficulty getting insurance at first—eh—tried most of the sort of standards and they were quoting anywhere from two hundred and fifty tae four hundred pounds to—one even went tae five hundred and something which I thought, you know, that’s a bit much and somebody told me tae phone the cancer travel organisation. —Andrew, age 55, (2/2)

---

<sup>14</sup> now at <http://www.macmillan.org.uk>

These expensive quotes were confusing to Andrew because he had actually been able to obtain very reasonable insurance for a short break before his surgery, and now that he was ‘cancer free’ the quotes had increased.

I was waiting for the operation I got the travel insurance from Marks & Spencer ...for twelve pounds. But when I phoned them back again after the operation tae try and get for this time they were one of the ones that was eh almost three hundred pounds and I didnae understand that—cause the cancer had gone, you know, I was almost a year after the operation, the wound had all healed. I hadnae had any side effects, any serious side effects and yet I had sort of, like, increased twenty fold, you know. I just couldnae get it at all. —  
Andrew, age 55, (2/2)

## 5.8 Chapter summary

This chapter has examined the experience of colorectal cancer as it impacts on the physical, psychological and social dimensions of participants’ lives. Under each of these three headings findings from the second interview follow findings from the first interview so changes in the intervening year can be observed.

The physical experience of colorectal cancer at diagnosis is most challenging during the hospital stay and as participants cope with bowel dysfunction as they recover from surgery. By comparison, symptoms of the illness have been mild. Overall, participants are pleased with their physical wellbeing although learning to manage a stoma requires effort and enduring chemotherapy is difficult. One year later, participants are surprised that bowel dysfunction, sexual problems and fatigue remain a feature of their lives although usually physical health allows participants to resume their previous lives.

A diagnosis of cancer engenders thoughts of death and therefore poses psychological challenges. The psychological impact is so great that participants may consider themselves changed by the diagnosis. Some struggle with low moods brought about by the fear of dying and also by the social restrictions they are enduring as a result of being physically compromised. Psychological support is provided informally by participants’ own social network. One year later

participants continue to work to understand their illness: what caused it and whether it still poses a threat to their lives. Some believe they are changed by the experience while others have assumed their pre-diagnosis sense of themselves. Their greatest psychological challenge now is living with the fear of recurrence.

The physical challenges of the illness have prevented participants from engaging in their usual employment, domestic, caring and social activities. There are financial implications for those who are working and for whom absence from work results in a reduced income. The benefits system is opaque and failed applications cause distress. One year later, life is largely normal in the participants' social sphere, although effort and ingenuity are required to manage ongoing bowel dysfunction while working, travelling and socialising.

## 6 Colorectal cancer patients experience of health care

In this second findings chapter the focus is on participants' experience of health care at diagnosis and at one year after diagnosis. The greater weight of this chapter is concerned with the experience of health care described at the first interview as this reflects the weight accorded to discussion of health care in the interviews.

### 6.1 Experiencing primary care at diagnosis

GPs played a key role in the diagnosis of colorectal cancer and this was most usually a straightforward process. There were, occasionally, instances of participants perceiving delays in their diagnosis. After hospital treatment a less uniform picture of the contribution of GPs emerges, with some GPs contacting participants on their return from hospital and others not.

#### 6.1.1 GPs and diagnosis

Often participants began accounts of the experience of colorectal cancer by describing visiting their GP with symptoms. Typically participants were referred straight away.

I went to the Doctors on the Monday and they got me an appointment with (hospital)—I think it was within a fortnight. —Tracey, age 46, (1/1)

The Doctor seemed to pick up the symptoms very, very quickly. — Harry, age 81, (1/2)

I had the diarrhoea and it widnae stop and it was him that sent me into the hospital—that's what it was—it was him that sent me into get this done. —Samuel, age 81, (1/2)

Alice described a locum GP checking that she would attend for a colonoscopy (an examination of the large bowel and the distal part of the small bowel with a camera on a flexible tube passed through the anus) in spite of negative FOB test results.

When I went to see her to get the results of the first two tests—which they told me were all clear—nothing showing up at all, she did say to me ‘You will go for the colonoscopy?’ I said ‘Oh yes’. —Alice, age 69, (1/2)

Doris’s GP referred her to secondary care for investigations straight away but she underwent a series of investigations as an in-patient before receiving a diagnosis.

I went to my Doctor and I had a low blood count... So then they sent for me to come up to go through a few tests, so they admitted me to X Hospital and I was there for sixteen days, getting CT scans and blood taken and just tests all that time. —Doris, age 84, (1/2)

It was during the visit to his GP to inform him of symptoms that Harry first realised he may have cancer.

I thought I’ll go and see the Doctor. So, I went down to our practice and there was an absolutely new Doctor I’d never seen in my life before. So I told him the symptoms and the boy said ‘Is there any history of cancer in your family?’ And unfortunately, yes, there is. My sister died of cancer. She had the bag and the colon and it was rather nasty. So, from then on in, I realised that maybe it’s something a wee bit more drastic. —Harry, age 81, (1/2)

There were instances of GPs spending time treating participants for conditions other than colorectal cancer before referring to secondary care. Danny visited his GP with what he believed to be a urinary tract infection and was treated for one, with a variety of antibiotics, before eventually being sent for x-rays when kidney stones were suspected. His kidneys and bladder were then investigated before the primary tumour in his colon was finally identified. Danny admitted to



feeling frustrated with his GP at the time but became, with hindsight, more understanding. His philosophical take was shared by others who had endured a more protracted route to diagnosis. Kirsty was treated for IBS when she visited her GP, on multiple occasions over two years, with flatulence. In the end, a rectal bleed prompted a referral but Kirsty understood that, at 37, she had been an unlikely candidate for colorectal cancer.

She took swabs and they seemed to come back clear and there was no blood in it then, so I don't know whether it was hard to tell. But then I suppose there's no use living in the past now, really, is there?— what's done is done. —Kirsty, age 37, (1/2)

Clive, who was referred promptly by his GP after passing blood, suspected that an oversight had occurred a year previously, when he had attended with the same symptoms and hadn't been given a colonoscopy.

A year or so later—it might be slightly longer than that—I'm a bit vague on the timescale—I got the same symptoms again, went and my GP said 'I think we'll just send you, you should have got that the last time, I think we'll send you for a colonoscopy, I thought 'well fair enough', you know. —Clive, age 59, (1/2)

There were unusual instances where GPs did not feature significantly in diagnostic routes. Jacqueline learned after surgery for a endometrial tumour that an additional tumour had been found and removed from her colon during her operation. Lorraine had been working in North Africa when she became unwell. She returned home and was initially sent for tests to a centre for infectious diseases before eventually undergoing a colonoscopy.

### **6.1.2 Delay and dissatisfaction**

Although it was not unusual for GPs to pursue other avenues of investigation before referring participants to secondary care, there were a minority of instances where participants felt that the time between their initial presentation with symptoms and their referral to secondary care was unnecessarily long and constituted poor care.

Glenda paid for investigations privately when she felt her GP was ignoring her plight. She had not been referred, after repeated visits, with bowel and abdominal symptoms.

Stephanie had consulted her GP 'at least a dozen times' in a five month period with stomach cramps and pain in her side. She was treated for Irritable Bowel Syndrome and told that her posture may be to blame for the pain before a rectal bleed prompted investigations. She felt that her GP should have referred her much sooner and, as a result, had lost faith in his abilities.

They could see from my record I very rarely go to the Doctors so that should have been taken into account as well, then there's something really wrong with her here. It was only a rectal bleed, really, that sort of got them moving. —Stephanie, age 53, (1/2)

### **6.1.3 GP contact on return from hospital**

Some participants were contacted by their GPs on their return home from hospital after surgery. GPs either telephoned or called in person and offered their support and enquired about participants' recovery. This contact was unsolicited and was appreciated by participants who were comforted by the knowledge that help was available.

I think, actually, she got in touch with me when she got the report from the Consultant and she just wanted to make sure everything was alright but that was very encouraging as well. —Scarlett, age 72, (1/1)

She came straight away. —Jacqueline, age 55, (1/2)

Some participants had clearly expected to be contacted on their return from hospital, they thought it routine practice or the result of a personal relationship with the GP

Yeah, just after em I was home I think it was a kind of routine visit, actually, she came up on. —Harry, age 81, (1/2)

She came and saw me, she was just passing doing house rounds one day, but I know her kind of personally as well, you know, she just popped in to see me. –Kirsty, age 37, (1/2)

Others were surprised, but pleased, by unsolicited contact.

My GP phoned me one morning, shortly after I was home, which I was quite surprised about, and just asked was there anything at all they could do for me at that point. –Muriel, age 68, (1/2)

There were occasional accounts of GPs continuing to phone or call on participants to check on their progress.

Where GPs had not phoned or visited, the lack of unsolicited contact could be a source of disappointment or dissatisfaction.

I thought he might have phoned me when I came out, you know, just to say ‘How are you doing?’ but och, well, the man’s busy so it disnae matter... I was a wee bit disappointed—I thought he would have given me a wee ring, you know. –Doris, age 84, (1/2)

Teresa was aware that her neighbour had been visited by her GP and expected that she, too, would receive a visit.

I think she should have come because somebody said ‘You’ve had a fairly serious illness’. I know that the lady upstairs—poor Gina’s dead now—it was a brain tumour she had and they didn’t get it all out—and her GP came to see her a couple of times. And I thought, my Doctor is really very nice she listens to you and she’s got a lot of time for you but I was disappointed, in a way, that she didn’t come and see me. – Teresa, age 70, (1/2)

Geoff’s wife’s expectation of a visit was based on it having happened in the past when she had been in hospital.

That was the procedure—I mean, I was only in twice but my Doctor came out to see me the day I was discharged. —Geoff (wife) (1/1)

Clive hadn't been contacted by his GP and believed his GP was 'shying away' from him.

Elsewhere participants didn't expect unsolicited contact. They saw no need for such contact as their needs were provided for by secondary care.

I took it for granted that eh everything was okay and that the hospital would deal with me if anything, they would know what would be wrong and that, you know. —Samuel, age 81, (1/2)

Additionally, they thought secondary care would update the GP on their progress. Some participants who were seeing the district nurse were confident that the nurse would communicate with the GP about their progress.

#### **6.1.4 The role of the GP, post diagnosis**

While GPs played a key role in the diagnostic process, typically referring participants to secondary care, they featured much less in accounts of care after diagnosis.

The last time I saw my doctor was when he got me my appointment for (hospital) and that was months before I had my operation. —Geoff (1/1)

Where GPs did feature in participants' accounts of their care, they played a wide range of roles.

Sometimes GPs simply offered support. Expressions of support and willingness to help were recounted often by participants (whether or not there had been unsolicited contact on return from hospital.)

Just to see how I was and how I was coping and then, once the chemo started, I got in touch with her again, 'cause she wants to know how I'm coping with the treatment. —Scarlett, age 72, (1/1)

In some instances GPs flagged up the possibility of psychological issues arising with a cancer diagnosis and their willingness to help with emotional problems should the need arise. Jacqueline became 'totally paranoid' when she had been sick on her return from hospital and appreciated her GP's reassurances that the sickness, and the paranoia, were to be expected as she recovered.

GPs were called upon for colorectal cancer-related advice and help: with infected wounds; wounds which weren't healing; diarrhoea; faecal urgency; constipation; an infection in the bowel and a urinary tract infection. Consultations for medical issues could provide an opportunity for GPs to acknowledge the cancer diagnosis and offer support.

Because it's a wound, it's difficult for me to see, actually, just where it is in my stomach but em I was happier getting them to do it and just to make sure everything's clean and there's no infection and if I needed to, you know, have a chat to the GP. –Danny, age 51, (1/1)

I had this in a wee bit of my wound and I had to renew my prescription, you know, just to get more paracetamol and that, that's what it was. And, I mean, he was really, he said to me 'It's worked out well the way it's happened for you.' I mean, I think he was even surprised how quick it all happened. –Meg, age 65, (1/2)

Chemotherapy, which typically lasted six months, led to side effects and GPs were asked for help with sickness, nausea and asked to reassure that other problems were indeed side effects from chemotherapy. Kirsty's GP did blood tests before she attended for each cycle of chemotherapy so that the blood tests did not need to be done at the hospital.

He'll do the blood on Friday before my chemo, I'll go up on the Monday to see (doctor), he'll prescribe the chemo and then I shouldn't be there very long. –Kirsty, age 37, (1/2)

Managing medication was a role GPs commonly carried out. Clive's GP was supporting his efforts to lose weight and had prescribed a weight loss drug so that he would become fit for surgery. In some cases medication had been

altered in hospital and GPs were responsible for monitoring the altered regimes. Complex medication regimes were common as participants dealt with pain, side effects from treatment, and other illnesses.

Making sure what I'm on is okay. I'm not reacting to anything badly and things are as effective as they can be and obviously picking up because I'm on antibiotics as well, in case they need to change it or, you know, give me another one, if there's any other bugs about. —  
Danny, age 51, (1/1)

Harry had accessed GP services out of hours when he became ill at night. The doctor who had visited him admitted him to hospital.

I had a pretty bad spell and some of my kids got a Doctor out during the night visit and they were talking on this 24 hour thing, you know. —Harry, age 81, (1/2)

Although GPs are portrayed as keen to support patients with regard to their cancer there were occasional mentions of GPs avoiding discussions about cancer. Both Tracey and Clive had seen their GPs, about other issues, but both felt that their GPs did not want to discuss their cancer.

She got me very, very quickly aye but eh—as I say—they don't ask me about the cancer. —Tracey, age 46, (1/1)

I got the feeling he was shying away a bit, too, himself, you know, em he's a fairly young man and his father was in the practice beforehand. He's an excellent GP—he really is first class—and a great manner—none of this old stuffiness and as far as I'm concerned, very able, as far as I can judge, but I felt this he was standoffish about this. —Clive, age 59, (1/2)

Often participants' contact with their GP post diagnosis did not relate to their cancer. Participants attended for help with a range of problems including eye, throat and vascular conditions.

I had other problems with my throat and infections like that. –Berta, age 50, (1/2)

Some participants had attended their GP regularly for routine checks, such as blood pressure, or management of chronic conditions, such as arthritis, prior to their surgery and these arrangements were resumed on discharge from hospital.

Concerns about the psychological and social aspects of colorectal cancer were broached with GPs only ‘in passing’. A few participants did mention their anxiety to their GPs and received reassurances. Berta’s relationship was challenged by colorectal cancer and she planned to consult her GP for advice as she felt her unsupportive relationship with her husband was compromising her ability to recover. Kirsty wondered whether she should contact her GP or stoma nurse with queries about sex and her stoma.

There were instances of GPs carrying out administrative tasks to help participants, for example, providing sickness certificates for work. Berta required a letter detailing her condition to support her sister’s visa application so that her sister could visit from abroad to support her. Tracey’s GP applied for a grant from a cancer charity to help alleviate the financial hardship she was suffering as a result of her cancer.

### **6.1.5 Interacting with nurses in the community**

Nursing care was required by some participants after their hospital stay, usually to care for wounds. Participants gave accounts of being visited by a nurse on their return home.

It’s left big raw marks right doon the bottom of my stomach. So I had it for a couple of weeks and they were just bathing it, the other Nurses, but this big one she went like that and stood there and went on the phone to the Doctor and got me a wee tube of something to spray on it and it was away in one day. –Maisie, age 64, (1/2)

And everything seemed okay and they were quite happy wae it and the second time they came she says ‘Well you don’t need anymore

dressings—it's healing up great' so that was more or less it—we didnae need any help. —Charlie, age 72, (Wife) (1/2)

Well, yes, the District Nurse came twice to look at the wound. —  
Philippa, age 64, (1/2)

Participants commented that the hospital must have informed the GP surgery as they hadn't needed to request nursing help and the nurse had visited soon after discharge. The amount of input required varied with some participants requiring just one visit and some being visited on a daily basis for six weeks. Sometimes participants required nursing care for issues other than their colorectal cancer, for example, Geoff required care for a vascular wound. Nurses advised on issues that were raised opportunistically by participants while they were visiting to dress wounds. Although the visits were primarily to manage wounds participants mentioned that the nurses had 'boosted them up' and encouraged them in their recovery. There are descriptions of nurses relaying information on participants progress to GPs and expressions of confidence in the channels of communication between districts nurses and GPs. (Although some participants were unaware of the close working relationship between district nurses and GPs.)

Other participants visited a practice nurse at their GP's surgery to have their wounds dressed. Geoff struggled to afford to pay for a taxi to the surgery twice a week to have a wound dressed and was delighted when the arrangements were altered so that the nurse visited him at home.

Participants described other contact with practice nurses, for example, attending for routine tests and routine clinics for chronic conditions such as diabetes.

Nursing care was highly valued by participants.

Oh aye, the Nurses aye, the Nurses were good, the Nurses were there every morning, definitely good, aye. Aye—if it wisnae for them, it's them that's daen all the work really, innit? —Maisie, age 64, (1/2)



### 6.1.6 Satisfaction with primary care at diagnosis

Overall, participants were most satisfied with their primary care's contribution to their care. Both Danny and Philippa articulated a particular strength of GPs as being the only clinicians in a position to take a holistic approach and monitor overall wellbeing.

When your GP sees you, literally, and sees what condition you're in. You know, they can tell a lot from that, I think, in terms of your skin tone and sort of general attitude. —Danny, age 51, (1/1)

She's terrific, terrific, really super and she's one of those GPs who doesn't just look at your sore big toe—she looks at the whole person. —Philippa, age 64, (1/2)

Dissatisfaction with GPs was usually associated with the time taken to diagnosis.

I want to complain profusely and I want to change my GP but I'm not strong enough for a fight just now. —Stephanie, age 53, (1/2)

However Andrew's dissatisfaction was because he considered his GP had not examined him thoroughly when he had visited with rectal bleeding; the GP diagnosed haemorrhoids, but referred him 'just in case'. The GP had not examined Andrew and had misdiagnosed him as having haemorrhoids. Moreover, the GP had not apologised when the diagnosis of haemorrhoids turned out to be incorrect.

It widnae have cost a lot of time for him tae put some gloves on and some jelly and had a grope round about my back passage which, you know, widnae have made any difference to the outcome it would still have been cancer but I'd have felt as though he was performing the way he should, the way I'd expect him tae perform. —Andrew, age 55, (1/2)

I would have thought he might be (more thorough) especially as I think (Laughs) his diagnosis was haemorrhoids and it turned out to be colon

cancer. If it had been me personally I'd have been in touch tae at least apologise for what had happened. —Andrew, age 55, (1/2)

In other cases, frustration with care provided by GPs predated the cancer diagnosis. Maisie wanted to change her GP, and had wanted to do so for quite some time, because she felt he too readily dispensed prescriptions and offered no other help.

You phone back and talk to the Doctor, say such and such, he says 'Right, I'll leave a prescription for you'—I mean, you could be saying anything and he's leaving a prescription for you. It's no real. —Maisie, age 64, (1/2)

Hugh also voiced dissatisfaction at medication being the only option offered by GPs.

It's all bleedin tablets the noo intit, I think it's all tablets the noo. —Hugh, age 48, (1/2)

Issues with accessing GPs were described. Both Stephanie and Maisie felt receptionists failed to facilitate access to GPs and Maisie described long waiting times for appointments.

Other than, like, stamp your feet and go banging on the door saying 'Look, I really think I'm very ill here' you know, you can't get past the receptionists. —Stephanie, age 53, (1/2)

It's three weeks if you phone up for an appointment wae them—you've got to fight wae them to get an appointment. —Maisie, age 64, (1/2)

Maisie had been unable to arrange a house visit with her GP when she had felt too ill to visit the practice.

No, I says to him when I went doon, I said 'I'm no fit I cannae come doon' and he went like that—he says 'Oh, we don't go oot now'. — Maisie, age 64, (1/2)

A GP had made a house call when Jason had requested one, but Jason's wife felt they had been reprimanded for requesting the service.

She was quite abrupt—she felt that em he came out of hospital on Friday and this was Monday morning and she felt he could have been at the Health Centre, which was a bit far fetched. —Jason, age 76, (wife) (1/2)

Maisie felt abandoned by health professionals in general after her discharge from hospital but it was her GP that she believed should provide on-going care.

I think the Doctor should take up a bit mair, a bit mair back-up for you, you know what I mean, they've no enough... efter your surgery and that and thingmy—I don't think there's enough care, you know what I mean, really, you're jist kind of left—well, that's the way I felt. —Maisie, age 64, (1/2)

For the most part, however, participants found GPs accessible and accounts of GPs encouraging participants to contact them for support are common.

She's very approachable. And, I mean, if I was to phone and say 'Look, I don't think I can come to the surgery', she would come up to see me. —Scarlett, age 72, (1/1)

While Harry had no complaints with his GP, he was not keen to visit again as he did not want any more blood taken after his hospital stay.

But em I used to go regularly for blood checks and things like that but eh, well, after the hospital I had so many pins stuck in me I didn't want to get more, you know. —Harry, age 81, (1/2)

Stephanie felt her cancer diagnosis enabled her to negotiate access to the GP more easily.

It's a case of, you know, I'm a cancer patient—I'd like to see the Doctor today. —Stephanie, age 53, (1/2)

## 6.2 Experiencing secondary care at diagnosis

Learning the diagnosis of colorectal cancer was the central 'event' of the experience of colorectal cancer and in every case was vividly recalled. Participants usually received their diagnosis during a secondary care consultation clearly intended to deliver the diagnosis and treatment plan. However, as was suggested in chapter five, these interviews highlight that it is not always at this consultation that participants learned they had cancer. As well as diagnosis the experience of investigations, hospital stays for surgery, and contact with secondary care post surgery is detailed.

### 6.2.1 Confirmation of diagnosis and treatment plan

Participants described in detail the consultation when they received their definitive diagnosis. It was at this same consultation that treatment plans were outlined. The majority of participants were offered surgery (with curative intent).

We sat doon and he sat and he looked at me and I says it disnae look too good, you know, and he says 'We've discovered a cancerous mass in your bowel.' —Jason, age 76, (1/2)

He said to me 'You know there are two types of polyp—benign and malignant' and he hesitated and I said 'Well, what is it?' and he said 'I'm afraid it's malignant—you've got cancer.' —Teresa, age 70, (1/2)

He was so nice—he got down on his knees beside me, you know, looking into my face and he said 'It's cancer'. I think maybe he expected me to break down or something but I had no need to break down or anything—I just said 'Oh is that so? Is that what will have to be done? Oh well, we'll leave it at that.' —Doris, age 84, (1/2)

Participants talked about feeling relieved when they learned that surgery was planned as it meant their cancer was operable. They described their treatment plan being relayed with confidence and optimism, from which they took faith, and that consultants had been pleasant, sympathetic and businesslike.

(Doctor) explained that they had found a lump on the colon and em it had proved to be cancerous. So the question was, what are we going to do about it, and em he recommended that they would cut above and below and remove that piece. Now he said 'It's a pretty big operation but I think that will be fine and we'll get you through it'. — Harry, age 81, (1/2)

I knew myself before he told me but, give him his due, he came straight in and took me into the office and, to be quite honest, the way he told me it, it was really good—I mean, I think I got my confidence right from the word go. —Meg, age 65, (1/2)

Usually the surgeon would describe planned treatment and often the specialist nurse was present and in some cases provided additional detail after the meeting with the surgeon. Side effects from surgery and other treatments were explained.

Participants reiterated the surgeon's description of what the surgery involved with great attention to detail, for example, they remembered the measurements of cuts. Andrew described how the surgeon had explained that the position of tumour prevented the bowel from being rejoined and therefore a permanent stoma was necessary. He also understood that his treatment had been discussed at a multi disciplinary meeting.

Participants felt they understood their illness, their proposed treatment and the rationale for their treatment and that it had been explained in appropriate terms for them.

So everything he laid it out in sort of laymen terms—which was great because cancer has always been a big scary word, but I think if people

sort of break it down and define it in terms that normal people can understand, then it disnae become as scary. –Andrew, age 55, (1/2)

### 6.2.2 Participants suspecting cancer

Although these consultations were clearly set up as the event at which the diagnosis would be given, very often participants had interpreted clues and become suspicious, or in some cases certain, that they had colorectal cancer. Clive who was told at colonoscopy that he had cancer, had already guessed from the demeanour of the staff during the investigation.

But shortly into it, I got the pre-med thing, you know, the sort of—I don't know what it is—whether it's a tranquilizer or whatever, but I sort of woke up from that and realised there was a bit of a panic going on and I was quite conscious of all this and I knew exactly they'd found something—I mean you can tell with people's reactions and suddenly a Doctor was brought into it. –Clive, age 59, (1/2)

Meg felt she knew when she was the only one of three participants who had undergone a colonoscopy who was asked to stay behind.

There was another three people in but when the Doctor actually did the bowel investigation, he told me right away—he said to me he wanted me to stay behind. –Meg, age 65, (1/2)

Scarlett suspected she had cancer from the way her doctor had been speaking to her.

I just got a feeling, from the way he was talking to me I knew, there was definitely something there, but I had a feeling it was cancerous—which it proved to be. –Scarlett, age 72, (1/1)

Kirsty had phoned after her colonoscopy and suspected she had cancer after receiving a message that her results were 'too complicated'.

I knew, I just knew, because when she told me that day and I got out and then a week later, the week in between, I was to go to see her

and I phoned up because I knew the results would probably be through and the secretary had said (doctor) just told me to tell you that it was too complicated to go into over the phone'. So I knew, I knew there was something, I knew it wasn't cut and dried. –Kirsty, age 37, (1/2)

Hugh described how he failed to interpret a clue, health professionals had phoned his wife and asked her to join him for the consultation but he was still surprised to learn his diagnosis.

Oh yeah, phoned my wife and says 'You better come up because we don't only want to talk to Hugh—we've found out what the problem is, but we need to see the wife, the spouse, to explain.' I just looked and went 'So'. Do you know what I mean, I never even clicked on cancer. –Hugh, age 48, (1/2)

### **6.2.3 Diagnosis at investigation**

Some participants describe learning they have cancer immediately following a sigmoidoscopy (an examination of the large bowel with a camera on a flexible tube passed through the anus). This conversation, with the health professional who had carried out the investigation, could be interpreted as a diagnosis. Andrew felt that the judgement of the health professionals carrying his sigmoidoscopy was likely to prove correct, so for Andrew, it was during this interaction that he received his diagnosis.

When I got dressed again the Endoscopy Nurse took my wife and myself into the office and very upfront saying 'We're looking at cancer here, cancer, but we'll wait for the results of the biopsy'... These people are experts so if they say it's cancer, they've had enough experience in the field to sort of recognise that—and I was quite happy to take the visual inspection there and then. The results obviously came through about a week, two weeks later and we were back up again and it was confirmed that it was cancer. –Andrew, age 55, (1/2)

Similarly, Charlie said he learned he had cancer during the conversation following his sigmoidoscopy.

Charlie says 'Is it cancer?' she says 'Well, we've done a biopsy—it'll be sent off and there is the chance at the back of your mind it could be.' I take it that she would maybe know by looking at it, have a half idea but she says 'We're not sure till we do the tests, but there is the chance it could be', so he accepted that. —Charlie, age 72, (wife) (1/2)

Although Tracey described the same sequence of events, and a similarly worded conversation, she clearly felt she learned she had cancer at a later date, when the CNS phoned to confirm biopsy results.

He had a wee word with me and said he was relatively sure that it was cancer I had, but he would have to get the Doctor's final opinion on it. —Tracey, age 46, (1/1)

Maisie's description of a diagnostic investigation suggests a limbo like state where cancer is suggested but not confirmed.

I went for a camera up thing to get examined and efter I had it done she came back and she said I would need to go for a scan she said it was blocked, she said that she thought I had a tumour and she couldnae get seeing right roon it, you know what I mean? —Maisie, age 64, (1/2)

Philippa also learned her diagnosis at investigation. In her case she was informed during the investigation with what appears to be an unplanned disclosure.

The consultation when they told me was pretty horrendous, I must say, I was lying on the bench with the periscope right up as far as it would go and I had refused sedation, which I had always done before that as well. And my Gastroentrologist got a fright because he is a friend of mine and he had looked the previous year, a year ago and he didn't see it. And he'd looked four years ago right up and it wasn't



there, well, he didn't find it, it wasn't there presumably. So he got a shock—I'm quite sure and unfortunately told me when I was lying there helpless on the table and that was not funny, I have to say and I'm sure it was because he got a fright himself. —Philippa, age 64, (1/2)

Philippa suggestions for what might constitute a more appropriate diagnostic consultation are more akin to the consultations described earlier where diagnosis were confirmed and treatment plans were outlined. Philippa is aware that one component of a more satisfactory diagnosis would have been someone, in her case her husband, being with her.

I think it might have been easier for me if he had said something like em 'I see something that I'm not too happy about—go and get dressed and we'll get your husband and we'll talk about what should be done, what it might be and what we should do about it.' —Philippa, age 64, (1/2)

Lorraine was also alone when she learned she had cancer, again, from the person who had carried out her investigation.

So, then, finally, when I was put up to a ward a young Surgeon came to speak to me, a young girl, and she done the final kind of scope and I said to her 'Well, what is it then?' and I was on my own and she said 'Well, it's a tumour' and I said 'Any chance it could be benign?' and she said 'Well I don't think so by the look of it and by the feel of it' and I said 'So it couldn't be haemorrhoids then?' (Laughs), 'No', you know, so that was that. —Lorraine, age 34, (1/2)

#### **6.2.4 Investigations**

A series of investigations usually followed the diagnosis of colorectal cancer and these were comprised of some combination of MRI, CT and ultrasound scans. Most participants understood that these looked for any spread of cancer. Andrew, who had a rectal tumour, described learning the stage of his cancer after scans.

In some instances, investigations were remembered as extremely unpleasant. The preparation for colonoscopy posed problems because drinking the bowel preparation medication and emptying of bowels could be uncomfortable. Philippa describes a significant impact from not being able to eat before or after a series of laxatives.

I had a CT scan which meant a third laxative, which was very hard for me because I'm very thin and I lost a lot of weight because of it. I had two laxatives within five days I think, six at the most, but then you can't eat before it and you can't eat after it very well and so I was very starved. –Philippa, age 64, (1/2)

Whether participants found the colonoscopy itself uncomfortable largely depended on whether or not they had been sedated. Most were offered sedation and accepted. Those that didn't found it 'gruelling' and 'agony' with the exception of Samuel, who was not sedated and did not report discomfort. Doris had refused sedation because accepting would have involved calling on (bothering) a doctor to administer the sedation.

Doris also experienced further discomfort during the CT scan as her arthritis made staying still for the duration of the scan painful. Jacqueline found the MRI scan a challenge as she suffered from claustrophobia.

### **6.2.5 Treatment plan**

After the initial shock of diagnosis participants were relieved to learn that their cancer could be treated and were keen to focus on their treatment plans.

I was, you know how you get, this isn't happening and it was explained 'oh' he says 'It's treatable and curable and we'll do everything we can.' – Teresa, age 70, (1/2)

Overall participants were pleased that their treatment plan was delivered with their diagnosis but occasionally this did not suit participants; some participants struggled to take in the treatment plan as they were too shocked by the diagnosis.

Treatment, for most participants, involved surgery. Those with colon tumours would undergo surgery with or without adjuvant chemotherapy afterwards and those with rectal tumour would receive radiotherapy and then surgery. Surgery was explained in varying degrees of detail.

I says 'Whit's transpired?' and (consultant) says 'We're going tae take two thirds of your bowel away.' I says 'Oh, I didnae know that', he says 'Yes, take two thirds of your bowel away'. –Jason, age 76, (1/2)

Some participants knew before surgery that they would require adjuvant treatment after surgery.

I had an appointment with (doctor) two weeks prior to that and he said he could give me an operation with quite a high success rate and, after that, a couple of doses of chemotherapy, just to make sure. – Tracey, age 46, (1/1)

There was uncertainty around elements of treatment plans. Stephanie's planned radiotherapy depended on a favourable kidney scan result. If the result had been unfavourable, then chemotherapy would be used instead. Participants were told that aspects of their treatment would be decided later, for example, whether or not the surgery would be open or laparoscopic, whether or not adjuvant treatment was required and whether or not a stoma was necessary. Muriel, however, was pleased to learn at the outset that a stoma was unlikely.

And then, from there I had an ultrasound scan and was told, yes that I had this small tumour in the back passage and yes, it was cancerous, so we would have to think about an operation and then (name) the consultant said 'I think we could possibly do a bit less than a colostomy' which I was very much relieved about and said 'Well, if that's what you think you can do?' and he said 'Yes, it's in a position where I think it's reasonably easy to get at so, therefore I don't think we need to go any further deeper to do the colostomy'. –Muriel, age 68, (1/2)

Where surgery was not planned treatment plans were particularly uncertain. Danny's initial treatment was based on alleviating immediate symptoms from his advanced cancer by draining an abscess in his groin. Chemotherapy had been mentioned as a potential treatment for Danny, depending on how management of his abscess progressed. Clive's treatment, specifically whether he could have surgery, depended on him losing weight. In the meantime, his treatment would be comprised of chemotherapy and radiotherapy in an attempt to shrink the tumour while he lost weight.

So then I went to (doctor) and he was excellent and examined me, of course, and explained what would happen, so the outcome of that was that I would get thirty treatments, of which I'm now into I think fifteen or sixteen, and I would have the chemo on a daily basis by tablet, which he said was a newer way of dealing with it. —Clive, age 59, (1/2)

### **6.2.6 The speed of treatment**

A strong theme present throughout the interviews is that of surprise at the speed of treatment. This speed was reassuring to most participants.

Participants were commonly able to recall key dates, for example, the date of diagnosis, the date of surgery, the date they left hospital and start and finish dates for chemotherapy or radiation treatment.

Those who received pre-operative chemo radiation for rectal tumours reported that treatment was planned and commenced with speed and they described their routines and said that the systems worked effectively with the exception of slight delays at busy times.

There was one instance of surgery being delayed by one week because of an emergency and this did not give rise to any dissatisfaction. Maisie asked for her surgery to be delayed, as she was frightened. Her request was accommodated. Meg visited her GP soon after leaving hospital to discuss the speed at which her treatment had taken place.

I spoke to my GP after the operation. Because it was so, so quick—I mean, although I'm saying to you I think I don't know if I'm getting over how quick it was, it was really quick. —Meg, age 65, (1/2)

The time taken from diagnosis to first treatment varied. Jacqueline learned about her cancer after it had been removed during surgery to remove a endometrial tumour. Muriel was told at diagnosis that her surgery could be done the following day, an option that she came to view positively.

So there and then he hit me with the idea that the following afternoon he had a slot which he could do the operation which really gobsmacked me at the time, but when I stopped and had a think about it, I realised it was probably for the best. And it was better not to really be thinking about it or having to wait—perhaps a lot longer time and perhaps things could have got worse. —Muriel, age 68, (1/2)

Alice received a phone message on the Friday asking if she could come into hospital the following Monday.

So came home, message... I'm in on Monday... Operated on Tuesday. —Alice, age 69, (1/2)

Stephanie was told she could take an arranged holiday and have surgery on her return but she opted to forgo the holiday and have surgery sooner. Participants noted the benefits of treatment taking place quickly. They talked about being glad that their cancer didn't have time to advance further and that they didn't have time to dwell on their diagnosis.

So I never really got time tae 'God I've got cancer' you know, 'you die wae that'—I never gied that a thought—everything was going that quick. —Jason, age 76, (1/1)

I have had great treatment from start tae finish, this country—I'm so glad I stay here. I mean, within being diagnosed a month I was in hospital and everything was over and done wae. Fantastic, absolutely. —Tracey, age 46, (1/1)

Not a lot of time was lost between the first me going down there and my operation being over. –Harry, age 81, (1/2)

### 6.2.7 The hospital stay

Participants talked about being surprised at how short their hospital stay was. They were also surprised at how quickly they were able to move, walk and eat after what they knew to be major surgery. Hospital staff were praised.

The nursing was absolutely wonderful, they were so nice, they were so kind and the Doctors were lovely and treated me not as a medical case but as a human being and I appreciated that and I wrote and told them so. I just appreciate that. It's so important in the care that you're treated like a human being. –Philippa, age 64, (1/2)

The Nurses are great and no only that the Surgeons, it's no your own Surgeon it's the Surgery Team and they're round nearly every morning and they're asking how you're getting on and what you want or what you're doing. –Samuel, age 81, (1/2)

There were occasions, however, where hospital staff were criticised for failing to provide adequate care.

One of the nights I was really, really sick but I did go off my head, nobody came. I was being sick all over the place and I'm shouting for a nurse, it was at night time—everybody was sleeping and nobody came. And then one of the nurses came in—I think it was about twenty minutes after it and I was covered, I was absolutely covered, and she says 'Oh my goodness I can't give you any more tablets' but (CNS) says she should have gave me it. I was in pain all night that night, absolutely horrendous. –Tracey, age 46, (1/1)

Philippa was surprised that the physiotherapist had ignored her request to teach her how to cough after surgery.

I would have thought that one of the things that a physiotherapist would know was exactly how to teach you how to cough post-operatively. –Philippa, age 64, (1/2)

Tracey's time in hospital had been so difficult that she asked to go home before her scheduled discharge date.

They wanted tae keep me in another two days and I said 'Why, what was the problem?' and he said 'No, just to be safe' I said 'No, I cannae sleep in here I want home tae my own house' 'Have you got help?' I says 'Loads of help—the minute I get out of here my brother will come and collect me, I'll phone my daughter, I can phone loads of people—I just want to go home to my own house.' –Tracey, age 46, (1/1)

### **6.2.8 Pathology results**

Seven to ten days after surgery participants received their pathology results in a scheduled consultation with the surgeon. At this consultation participants learned whether or not adjuvant treatment was required. Those who required no further treatment after surgery said they had felt great relief at that consultation.

He actually phoned me with the results of the biopsy and the great news that it was, he said 'It's the best possible news'. And he sounded so relieved and so glad about it. And I went to get it officially from the Assistant Surgeon and he was absolutely delighted as well. – Philippa, age 64, (1/2)

The second of February I went to the out-patient's clinic at (hospital) and saw the Professor who gave me the good news that they got it all away and I don't need any more treatment which was wonderful. – Alice, age 69, (1/2)

## 6.2.9 Adjuvant treatment

Issues with adjuvant treatment were described with participants feeling aggrieved at the long waits for appointments and long waits between having blood taken and waiting to see whether or not treatment could go ahead. Glenda felt that being on a trial had resulted with particular confusion with regard to her blood results.

My blood wasn't good enough, so they sent me home for a week and I came back and it still wasn't good enough, so I had to come in the next day and it was good enough they said, then they said it wasn't good enough because I was on the trial and it had to have a higher count than not on the trial. So, a bit fed up about that 'cause I've been up and down, up and down, up and down. –Glenda, age 67, (1/2)

## 6.3 The role of secondary care health professionals at diagnosis

The roles of three secondary care health professionals are described in the interviews: CNSs, Stoma Nurses and surgeons.

### 6.3.1 Clinical Nurse Specialists

The majority of participants spoke about the significant contribution CNSs made to their care. CNSs were a preferred source of advice because of their expertise, because they provided continuity of care and because they were accessible. Additionally, they provided emotional support to participants.

CNSs provided information on medical, practical and emotional aspects of colorectal cancer. CNSs' expertise extended from the illness itself to treatment, treatment effects and side effects and to the wider social and psychological implications of the disease. CNSs' expertise made them the preferred source of information for many, with a couple of participants mentioning that their CNS was more expert in colorectal cancer than their GP.



Early on participants appreciated explanations of what they might expect to happen.

She put it into sequence of events and when things would happen and I took a note there and then and that was a big help. –Scarlett, age 72, (1/2)

I met her, she came into, you're in a single room before your operation right, before you go down, the anaesthetist comes in he talks to you, the nurses come in if you're going to get a bag they mark your gut where things are going to happen and all this carry on. Then (the CNS) comes in and she's got a book there and she's talking to you, smiling and having a wee joke with you and calming you. –Geoff, age 75, (1/1)

They sought explanations of investigations from CNSs. Maisie was confused about the results of a scan and planned to contact the CNS for clarification.

Later, medical advice was sought on post operative issues.

I was concerned going to the toilet many times, many times, you know and she said that she was not surprised because usually because they cut near the rectum that's why she said she was not surprised I was going to the toilet many times. –Berta, age 50, (1/2)

So we did—I phoned (the CNS) to ask this was part and parcel because you don't want to be troubling her if it's something that's part and parcel of the operation. He was getting nausea in the mornings and she said 'Well, the ether—the anaesthetic can cause that' he was getting bouts of nausea a lot. –Geoff, age 75, (1/1) (wife)

In fact I was going to phone (the CNS) about that time I had em diarrhoea. –Charlie, age 72, (1/2)

Participants contacted CNSs for direction on practical matters such as obtaining travel insurance and benefits advice.

Continuity of care was provided by the CNSs who were present throughout participants' involvement with secondary care. One CNS carried out sigmoidoscopies and had told the participants in her care that cancer was suspected. Other participants had been introduced to a CNS at diagnosis and the CNSs had continued contributing to care throughout investigations, treatment and follow up.

CNSs were present during consultations with the surgeon and made sure participants understood what had been said and its implications for them.

She's usually there when I see the consultant and eh after the meeting she'll say, you know, 'If there's anything you don't understand'... so when we came out after the consultation she would go over it again. Because you're trying to take it all in just to make sure you've got it. —Scarlett, age 72, (1/1)

Participants found CNSs easy to contact. Participants were able to telephone the CNS and specifically mentioned having a direct line phone number.

You see (CNS's) card is up there and so is (stoma nurse's) and all I need to do is phone up their own lines—you don't need to go through the switchboard. —Teresa, age 70, (1/2)

They talked about the nurses' reliability in returning calls and about the nurses having emphasised their willingness to be contacted to provide assistance. In addition to their own expertise, the nurses would relay queries to the surgeon and inform participants of the surgeon's advice.

If I have some problem like this I always call (the CNS) and she always goes to (surgeon) and after that she calls me back and gives me the advice so probably I will do it again because when I was concerned going to the toilet many times. —Berta, age 50, (1/2)

That link I suppose between her and the consultant. And she's been able to pass information on to them and vice-versa. —Danny, age 51, (1/1)

The emotional impact of colorectal cancer was addressed by CNSs. They gave reassurances about treatment by explaining what would happen next and, in some cases, showed participants round the high dependency unit and introduced them to stoma nurses and other health professionals who would be involved in their future care. They discussed the impact of the illness with participants and participants' families. Danny said that the one person he felt able to talk about his illness with was the CNS. Jacqueline described discussing her fears about death with the CNS. Most participants said that the CNSs had urged them to get in touch if they had problems coping emotionally.

'Well certainly (CNS) has just been a great help about discussing, em, the current situation and also how things may develop and just really, you know, you need to, because you're not sure, you haven't been through this before you're not sure what may happen next. And just, you know, putting me at ease about what's perhaps happening with you and options that you have.' —Danny, age 51, (1/1)

Also just checking anything to do with like the, you know, the wigs or anything or feeling emotionally upset or if there's any other problems—family problems, anything like that—she's just there. — Jacqueline, age 55, (1/2)

The CNSs' role involved managing the participants' journey through investigations, treatment and follow up. They kept participants up to date with appointments and test results and arranged and coordinated investigations and care. Some returned to see the CNS at her follow up clinics after surgery.

Participants had initially lacked understanding of the CNS's role. Philippa had been fearful when first introduced to her CNS because she was introduced as a 'Macmillan nurse' which had connotations of palliative care and this seemed at odds with Philippa's understanding that she was being treated with curative intent.

Oh no, I was very daunted because the Nurse was introduced to me as the Macmillan Cancer Nurse and that was before I knew I had cancer and when the biopsies had said it was on the brink of. I thought, my

heart sank, I thought I'm sure I don't need a Macmillan Nurse.—  
 Philippa, age 64, (1/2)

In spite of the CNSs playing such a pivotal role in participants' care some had not initially known why they had been introduced to a CNS.

I was a bit vague on it all at that stage, I mean, I thought 'I'm going to see an oncologist—why would I want to see a nurse?'. I hadn't realised what was involved, you know, but when we got there, of course, it's a different kettle of fish. When you see them operating in their clinic and you're calling in to see them and all the rest of it. So their involvement's been very good. —Clive, age 59, (1/2)

### **6.3.2 Stoma nurses**

Stoma nurses also provided specialist help for those with stomas. This care began in hospital continued with home visits to ensure participants were managing their stomas after hospital. The stoma nurses also ran clinics which participants attended after discharge. They were described as helpful and examples of problems being speedily resolved by the stoma nurses were given.

I had a problem a couple of weeks ago with the bag and, you know, you sit and you worry and sometimes if you see someone like that—a professional—it's quite simple, it's quite a simple thing, the hole wasn't big enough (Laughs) so it was a silly thing like that but I was imagining, I said 'They'll have to give me something else.' —Teresa, age 70, (1/2)

They too were accessible and approachable and happy to advise on issues other than stomas.

Oh absolutely, I mean that's what the stoma Nurse said—she was in the other day and I was saying to her how much I'm eating, but she said 'You need to do that, you need to build yourself up'. —Alice, age 69, (1/2)

### 6.3.3 Surgeons

Surgeons received a lot of praise with participants expressing a high level of confidence in their skills and acknowledging that, in undergoing surgery, they had ‘put their life in his hands’.

You hear lots of people travel from all over the place to go to (doctor) and then you hear of her down in London doing operations, so you just think and you hear good things about her, so it’s very kind of reassuring when you’re putting your life in their hands. –Kirsty, age 37, (1/2)

(Surgeon)— I would put my life in his hands he’s a dedicated man, obviously dedicated, stands no nonsense but he’s definitely dedicated and he’s a wonderful surgeon. –Geoff, age 75, (1/1)

You want to see this guy—he jist looks at yae, ‘I’ll fix you in a minute,’ he says. And he did.—Hugh, age 48, (1/2)

## 6.4 Communicating with health professionals at diagnosis

Overall, participants appreciated the extent to which health professionals worked to ensure their understanding of their condition and their treatment. However, participants were sometimes reluctant to become involved in treatment decisions and remained confused over plans for their follow up care and monitoring.

### 6.4.1 Communication and understanding at diagnosis

The interviews contain evidence of significant effort on the part of health professionals to ensure participants understood their diagnosis and treatment. These efforts were appreciated. Andrew praised the communication skills of health professionals.

The oncologist again, same as the surgeon, same as the endoscopy nurse—very straightforward, tells it like it is, doesn’t try to flower it

up any way, told me exactly what would happen, gave me percentages which, I'm an engineer so I work in figures all the time and it's actually quite good. —Andrew, age 55, (1/2)

Andrew was also impressed by the readiness of health professionals to respond to his queries.

I'm the type of guy that likes to ask a lot of questions—I just don't accept things. I want to know what my medication was for, etc.—whether they were changing dressings and doing things that they were doing. And they always found time to give you an explanation which I don't think happens in the NHS certainly I've not got a great deal of experience, but I know years ago if the Doctor said that was it and God gave you the tablets down from the mountain and you didn't question anything and it was very difficult to get information but now they're so open—I think it's great that people don't see it as a sort of black art any longer. —Andrew, age 55, (1/2)

Similarly, Kirsty made numerous phone calls to health professionals and felt that her concerns were addressed and she was never made to feel she had been phoning inappropriately.

Even my friend Jane said 'Were they alright about you phoning?' 'cause even yesterday when I spoke to (doctor) I said 'I'll be the bane of your life' and it's like 'Not at all, not at all', you know, whereas you can tell by the tone of their voice it's not as if—it's like, right, I've told you this before, you know, it's never been anything like that. —Kirsty, age 37, (1/2)

Philippa, too, was impressed with the readiness to address her queries and she acknowledged that different patients would have different information and communication requirements and preferences.

I have more knowledge than the average person, having done some medical study, actually, with my zoology degree and having read a lot

and my questions would therefore be different I guess. And my inside knowledge would be quite daunting, possibly. —Philippa, age 64, (1/2)

Participants often brought someone with them to appointments so that they could check their understanding of what they had been told.

When I was going for these sort of consultations, I usually had my daughter with me 'cause they do advise you to take somebody, because you are trying to take a lot in. —Scarlett, age 72, (1/1)

There were, however, some issues around communication and information provision. Sometimes the language used around diagnosis was cryptic and left participants struggling to understand what the health professional was attempting to impart. Scarlett was told that there was 'definitely something there', Danny was told that there was something 'a bit more sinister' and Andrew that there was an 'anomaly'. Kirsty was told that a polyp that had been removed had seemed 'a bit sticky' and when she questioned the surgeon further, was told that meant cancer was suspected.

Elsewhere medical terms served to confuse participants.

They don't explain it in English—they tell you in all these big fancy words, you don't understand anything like that. —Tracey, age 46, (1/1)

One area that seemed to be a source of confusion for participants was that of lymph nodes. They often would first hear lymph nodes mentioned when they returned to receive their pathology results post surgery but struggled to extract meaning from what they were being told.

See they says I've got two spores in the lymph nodes, wherever that is, I know they're under your arm, I know they're everywhere. But they never explained where mine was, I don't know if it's at the top of the bowel, the bottom of the bowel or if it's still of the bowel. I don't know a lot of things at all. —Tracey, age 46, (1/1)

She says it's an automatic thing but (the surgeon) never mentioned it.  
Six of the glands were taken away. —Charlie, age 72, (1/2)

While the manner and attitude of health professionals was usually praised Clive took issue with a surgeon's attitude.

Very abrupt, very offhand—'Oh this is a growth, no doubt about it, no doubt about it—cancer, you don't get cancers growing into other tissues'—I said 'Oh well, are we at that stage, do we know that?' 'Well, I'm pretty sure', he said 'But we'll get it tested and find out'. So, at that stage, he said 'I think I might have a look at it myself, so you come in on such and such a date and we'll sort that out and I'll try and get a biopsy'. So, fair enough, that was really horrendous, that was absolutely dreadful. —Clive, age 59, (1/2)

Stephanie was confused about her treatment. She returned home from hospital with a bag of chemotherapy drugs and was confused about which drugs were to be taken and when. The hospital clarified things for her when she phoned.

#### **6.4.2 Treatment decisions at diagnosis**

For the most part, health professionals described participants' planned treatment to them. Participants did not contribute to decisions about their treatment and did not raise their lack of input as an issue. Most participants were simply informed whether or not they would receive adjuvant treatment, a scenario that no one mentioned they were unhappy with. The opinion of medical staff was respected.

Cause I'm not a doctor or a surgeon or anything and he explained it all to me. —Kirsty, age 37, (1/2)

There were occasions where patient input was required and these tended to be decisions about chemotherapy.

Meg had been given the option of receiving adjuvant chemotherapy by either IV or tablet form. She found the idea of tablets appealing because it seemed less



restrictive and she was weighing this up against 5% better survival rate with IV chemo. She felt she had to take every percentage chance to improve her chances of survival and avoid regretting her decision in future. She had discussed her options with her family but they refused to sway her. She found the decision making process onerous.

I wanted somebody to say, I wanted them just to say that's the way it's to go (Laughs) it is easier, you know. –Meg, age 65, (1/2)

Jason was confused when he was offered adjuvant chemotherapy by the oncologist as he thought this was at odds with his understanding that the cancer had been completely removed. The oncologist agreed with him that he was unlikely to receive any significant benefit from chemotherapy and he was then comfortable deciding against it. Charlie was confused by the offer of adjuvant chemotherapy and wondered if 'maybe this is something they're experimenting with.' He wanted to be given time and further information in order to make his decision.

Elsewhere the decision making process posed no problems. Alice was given the option of pre operative chemo-radiation to reduce her chances of the need for a stoma. She refused, as she was able to be very philosophical about the prospect of a stoma.

He said we had a 50/50 chance that he could join me up again, but, if I wanted, I could have radio and chemotherapy to try and shrink the tumour and then I would have a 70/30 chance of reversing the situation. But I decided just to get rid and go for it, just go straight for the operation—the 50/50 chance, if I was to have a bag for the rest of my life—well, that was it. –Alice, age 69, (1/2)

Scarlett, who lived alone, elected to have her chemotherapy pump administered in hospital, rather than at home, as nurses would be on hand should any problems arise.

Kirsty was happy to be guided when she choose between a stoma and chemo radiation.

So they removed the polyp and then that's when they gave me the choice of the colostomy or chemo and radium, but because I was so young they kind of swayed me to the colostomy which anybody at my age would take. —Kirsty, age 37, (1/2)

At the time of interview a couple of men faced decisions about chemotherapy and they, too, were comfortable making the decision. Harry had an appointment to see the oncologist and had been briefed that chemotherapy may be offered but that he wouldn't be put under pressure to undergo treatment and that pros and cons would be explained to him. He thought he would prefer not to have treatment.

I would rather enjoy a nice wee bit of quality of life even if it's short rather than a longer term of suffering in pain. —Harry, age 81, (1/2)

Andrew, who had undergone pre-operative chemo radiation, had been asked if he would take part in a trial testing postoperative chemotherapy. He thought he might prefer not to have treatment and was clear that the oncologist was very sympathetic and understood that he had already spent a long time receiving treatment.

He's told me that it would help as regards collecting information. He's also told me that he's unsure, which is why they are having the trial, as to whether the chemotherapy would be beneficial tae myself. And he's also suggested that maybe—because this has gone on so long—that I might just want my life back and I'm still undecided yet as to how I'm gonnae go and I'll leave that tae I go up and see him. —  
Andrew, age 55, (1/2)

### **6.4.3 Plans for follow up**

Participants were aware that they would be followed up by secondary care but seemed uncertain regarding what follow up may entail.

I take it they'll be taking scans and different things frae there, you know what I mean. So I don't know whit'll be going on really I'll just need to wait and see. —Maisie, age 64, (1/2)

I suppose then I'll have to go for a scan maybe or something, I don't know or blood tests or something, I don't know what'll happen. — Glenda, age 67, (1/2)

I don't know—as far as that's concerned, I've no idea—you see, he went every so often to get his blood pressure checked and that's the only time he was in contact with his own Doctor. So, whether they'll get in touch with him for anything I don't know, we don't know that—they never said anything. —Charlie, age 72, (1/2) (wife)

Jacqueline wondered how her follow up would be arranged given that she had had an endometrial cancer as well as colorectal cancer.

I don't know how it works. If, when you have check-ups or—because obviously I've got this womb and the bowel thing and I'm thinking, you know, how does this, you know, you hear people talking about three months, six months check-up but I don't know how it works for me, if they wait till I've finished the chemotherapy and the radiotherapy before it actually, if I see a bowel consultant or if I see—I don't actually know—nobody's said to me and I've never had a letter saying, oh it's your three month check-up, or—so I don't actually know how that works, I don't know if I have to have a colonoscopy each year or you know, how they keep on top of it, how they will follow up with this.

—Jacqueline, age 55, (1/2)

Scarlett did, however, have a grasp of what her follow up would involve.

(Hospital) are definitely keeping an eye on things, you know—I've got an appointment again with the Consultant and I've another scan to have, you know, they're doing these regularly. —Scarlett, age 72, (1/2)

#### 6.4.4 Communication between primary and secondary care at diagnosis

Mentions of the primary-secondary interface pointed to effective communication. Communication from the hospital was surmised to have been the catalyst for the GPs' unsolicited contact after a hospital stay. Even where participants had not seen their GPs, they felt confident that secondary care had communicated their progress. Where district nurses had visited, they assumed this meant the hospital had made the GP practice aware of their needs and history.

I havnae a problem so I'm not going near my GP and he must have got my records from the hospital because the nurses started to come in when I got out. –Geoff, age 75, (1/1)

They seem to be well notified because (surgeon) said to me he said 'I'll be contacting your GP'. –Charlie, age 72, (1/2)

Danny described visiting his GP regularly to keep her abreast of his treatment—he believed a hospital's move to new premises had temporarily resulted in slower communication in his regime which was frequently altered.

I think, simply, it was perhaps just an admin problem and that wasn't an issue because I was going to see the GP on a regular basis anyway. –Danny, age 51, (1/1)

Tracey recounted an incongruous encounter which suggested ineffective communication between primary and secondary care:

They sent out one of the district nurses and I know her she's (surname) same as myself and eh I was talking to her and she says 'Tracey, I don't know why we're out here it should really be the hospital nurses you're dealing with.' I says 'Well, I don't know why you're here either then, who sent you?'—she says 'Em, the surgery but it's really the nurses at the hospital'—I says 'Well I wisnae told tae attend the hospital by any manner or means when I left, I asked them.' –Tracey, age 46, (1/1)

## 6.5 A preference for secondary care

Participants preferred consulting secondary care, rather than primary care, with issues related to colorectal cancer because secondary care was viewed as more expert and more accessible. Specialist nurses and stoma nurses were the preferred source of expert advice.

The problems I've had—it's the hospital that have taken care of them because she couldn't have dealt with a stoma bag I don't think her (the GP's) nurse could have either. —Teresa, age 70, (1/2)

They know exactly what you're talking about, rather than my GP. —Stephanie, age 53, (1/2)

Advice from secondary care was easy to access.

If I've got any problem I know I can phone her and she's always very helpful. She was the Macmillan Nurse that looked after me when I was in the hospital and she's a very nice person and I know that there's no problem. If I have any problem she's the one I would probably go to first. —Muriel, age 68, (1/2)

Some participants who described little contact with their GPs post diagnosis held the view that they were being cared for by secondary care. Responsibility for their care had shifted from primary to secondary care.

The hospital have been basically taking care of me and they've all been very supportive and trying to reassure you that things are going to be alright. —Muriel, age 68, (1/2)

The notion that they were the responsibility of secondary care may have been encouraged by the CNSs who had instructed participants to contact them with queries relating to their colorectal cancer or treatment.

She (the CNS) said 'Any problems all you do is phone me up'. —Teresa, age 70, (1/2)

Berta thought she would ask the CNS's permission to contact her GP.

I may ask (the CNS) if I can get in touch with my GP and try to find out—maybe, you know, talk to him if all these problems are really, you know, related with the operation. —Berta, age 50, (1/2)

Dissatisfaction associated with perceived delays in diagnosis served to erode confidence in primary care and made secondary care the preferred source of advice.

I wouldn't phone them, I've no confidence in them at all—even when I was poorly after I came home after seven days and I wasn't well, I really wasn't well. I thought I'll have to get a doctor out or something, I can't cope with this—I phoned the hospital and they said 'Just bring her in'. So I did that rather than phone my GP because they're more supportive. —Stephanie, age 53, (1/2)

## **6.6 Experience of health care one year after diagnosis**

One year after diagnosis contact with both primary and secondary care was reduced and the period of intense health care experienced by participants at diagnosis and during treatment had passed.

Interactions with primary care were seldom to do with colorectal cancer and those who had become dissatisfied with primary care one year previously remained so. Contact with primary care occurred in the context of follow-up regimes. As had been the case a year previously, participants valued the expertise of secondary care.

### **6.6.1 Experiencing primary care one year after diagnosis**

Many participants had had little or no contact with their GP in the months between their first and second interviews.

I haven't seen my GP at all. —Philippa, age 64, (2/2)

I've seen her now and again but I haven't really needed to see her, you know, em about anything really. –Jacqueline, age 55, (2/2)

Seriously, I don't go to my GP, I don't go even, do you know... I don't even think actually to go. –Lorraine, age 34, (2/2)

Those who had chronic conditions continued their previous arrangements.

About every eight weeks he checks my blood and blood pressure. –Doris, age 84, (2/2)

She was phoning this morning to see how I was getting on with the steroids and eh well I'm in regular contact with her, you know, to get medication and eh but apart from that. –Teresa, age 70, (2/2)

Contact with GPs was seldom with regard to issues associated with colorectal cancer.

Backwards and forwards kind of thing... nothing to do with the cancer. –Kirsty, age 37, (2/2)

Those who were seeing their GP regarding other issues occasionally mentioned issues related to colorectal cancer.

The last time I was there he was tying my shoelaces—I'd mentioned the hernia and he says 'Could I see it?' so he felt it over, you know. –Doris, age 84, (2/2)

A minority did consult their GP on the ongoing impact of their colorectal cancer, particularly the physical aspects such as hernias, fatigue and diarrhoea.

It's only been to do with the two things: my hernia and the diarrhoea. –Samuel, age 81, (2/2)

Clive was unusual in that the amount of contact he had had with his GP had increased since his diagnosis. His GP was continuing to treat his obesity and COPD.

A lot more than I used to have—yes, aye, aye, certainly, I would say maybe four or five times a year. —Clive, age 59, (2/2)

He discussed his treatment from secondary care, specifically the implications of his failure to lose weight, with his GP.

What my GP said to me the last time I was there ‘Have they kicked you off it yet?’ I said ‘They?’ she said ‘Aye, the Surgeons,’ so I presume if you don’t, you know, meet what they request, they just dispense with you (Laughs), you know, that was the sort of inference. —Clive, age 59, (2/2)

Clive felt that his GP’s role could have been expanded further to incorporate some of the tasks carried out in secondary care as attending his local GP was much easier than visiting hospital.

Maybe a lot of the stuff that’s done at hospital could really be done there, you know. —Clive, age 59, (2/2)

### **6.6.2 Satisfaction with primary care one year after diagnosis**

Those who had been dissatisfied with their GPs at the first interview remained aggrieved for the reasons described at their first interview.

Stephanie and Glenda were still dissatisfied about the length of time their diagnosis had taken. Their perception that there had been GP delay in diagnosis impacted their ongoing confidence.

I think I told you I went to her, I think four times and she told me everything was okay and then luckily I went to a locum and she was worried straight away. So I decided I wouldn’t go back to—whatever her name is, I can’t remember. —Glenda, age 67, (2/2)

Glenda thought that the GP had made assumptions based on her age and gender.



I think it is—it's because it's women who are, you know, not in the first flush of youth and I think they just think 'Oh a fusspot'—I genuinely think that. —Glenda, age 67, (2/2)

Teresa remained unhappy that her GP had not called on her after her hospital stay and Andrew was still disgruntled about not having been examined thoroughly by his GP.

I was a bit disappointed in her after my operation because eh so many folk said 'Your Doctor will make a courtesy call' and she didn't bother. —Teresa, age 70, (2/2)

He didnae examine me eh—left a kind of bad taste in my mouth. — Andrew, age 55, (2/2)

Those who were unhappy with their GPs wondered whether they should switch to a different GP. Andrew had voiced his dissatisfaction to the practice manager but did not feel his concerns had been addressed.

Like I say, there's absolutely no point—I did speak tae the Practice Manager but I got fobbed off there, I didnae feel that I got a lot fae the practice, you know. —Andrew, age 55, (2/2)

Elsewhere participants were satisfied with their GPs, with both their abilities and their manner.

I trust my GP to get in touch with me if she was worried about the results of any tests. —Philippa, age 64, (2/2)

He sits and looks at you when he's talking to you—he doesn't sit behind a desk. He sits a chair there and a chair there and he looks and listens, you know. A lot of Doctors just write away there at the other side of a desk and they're asking you things but they're writing, you know. Not him—he's a lovely big man. —Doris, age 84, (2/2)

### 6.6.3 Follow up one year after diagnosis

Treatment had been completed for most people by the time of their second interview. However, contact with secondary care continued with follow-up and unscheduled contact made by participants with concerns.

They don't sort of finish wae you, shuff you oot the door and then you never see them again—they're available tae you, even if it is just for a five minute chat. Sometimes that's enough just tae get you ower a wee bump, you know. —Andrew, age 55, (2/2)

Often the only contact that participants had with health professionals had been to do with their follow up, which could be quite an involved regime.

I saw (name) the Macmillan Bowel Cancer Nurse in October to take a blood test, I think it was October, yeah, the end of September, to take a blood test. And I saw her in April, April I think too, just coincidentally when I was checked by the Surgeon. And I had a CT scan in February, that's all. I haven't consulted anybody or seen everybody else. —Philippa, age 64, (2/2)

I've had two, two or three scans, I think I've had. —Andrew, age 55, (2/2)

Although they were established in their follow regimes at this point, some remained uncertain about future follow-up.

If it's any, you know, if it gets any less as time goes on or if it is an annual, permanently an annual thing, I don't know. —Alice, age 69, (2/2)

There was discussion of follow-up visits which were memorable, not least because of the need for colonoscopy and scans for some participants. Enduring investigations was challenging and taking laxatives was described as unpleasant.

It's absolutely hellish, it's supposed to be vanilla flavoured—it's the queerest vanilla flavour I've ever tasted (Laughs). —Alice, age 69, (2/2)

Some participants reported discomfort during colonoscopy or claustrophobia during scans. A range of other issues with follow-up were described. Alice was surprised to be sedated for a colonoscopy.

Professor (name) came in put some stuff in the free flow that they put in the back of my hand and that's the last I remember till I woke up, they actually zonked me and I didn't realise they were going to, you know. I thought I was going to be conscious while this was done. But I wasn't—they knocked me out. I thought they would have said, you know, we're going to, all he said was 'This will relax you'. Well, it didn't half relax me. —Alice, age 69, (2/2)

Colonoscopy had proved impossible for Doris, so a scan was used as an alternative.

They discovered that the bowel had healed but it had scarred and it had made it narrow and they couldn't get the camera through so he decided the next week to give me a CT Scan and that was when they said, no, they had managed to see everything and I was quite clear so far. —Doris, age 84, (2/2)

While Philippa was reassured by the monitoring follow up offered, she was not keen on the idea of regular scans.

I suppose so I've got to do it—I don't terribly like submitting my body to a CT scan which I assume is fairly high radiation—I don't know, I've no idea, I don't really know but I've got to do it, I've got to do it. It's better that they should find the tumour and take it out or a pre-tumour and take it out, isn't it, there's no choice. I'd rather not irradiate my body but I must do it. —Philippa, age 64, (2/2)

Maisie's results were temporarily mislaid.

I got a scan and then they couldn't find the results but they found them eventually and everything was okay. —Maisie, age 64, (2/2)

Perhaps the greatest challenge of follow-up visits was the catalyst they provided for fears around recurrence.

I just worry about the scans if everything's alright, you know what I mean that's all I'm worrying about noo. —Maisie, age 64, (1/2)

That side of it I can't deal very well with, you know, I'm so scared they tell me something bad, but everybody's feeling the same way and you just have to hope it's okay. —Jacqueline, age 55, (1/2)

Once you get the initial (laughs) fear, I mean, I'm coming up for my assessment again, obviously I just got the scan done there and that's worrying but, you know, I'll fret a bit 'til I get there next week and they tell me either good news or bad news. —Andrew, age 55, (2/2)

#### **6.6.4 Secondary care health professionals one year after diagnosis**

Secondary care health professionals were viewed as caring and accessible and participants had continued to contact them with cancer-related queries beyond routine appointments.

They're a good team up there at (hospital), and I know that they cannae get involved in every patient's case tae a degree, but they certainly do come across as being caring professionals, like, which is, in this day and age, pretty rare. So they had sort of encouraged me actively before the operation, when I was first diagnosed, if I had any problems at all—it didnae matter what the issues was—tae phone them first—they would be the point of reference and they would try and guide you tae where you wanted tae go. —Andrew, age 55, (2/2)

A year later contact with CNSs in the intervening months was reported as having taken place at routine follow-up appointments. Participants, however,

mentioned again that they found having a CNS's phone number very reassuring even if they did not use it.

It's mainly (CNS) I depend on, you know what I mean, it's definitely no doctors. I know they're busy—they're busy, busy people aren't they? —Maisie, age 64, (2/2)

Some said that if they were going to seek help on matters related to colorectal cancer they would first consult a CNS.

Participants had had contact with surgeons at follow up clinics, and as had been the case at first interview, they were held in high regard.

I had great faith in (surgeon). I felt he really—I mean he wasn't pally or anything—but I felt he really knew what he was doing. —Glenda, age 67, (2/2)

### **6.6.5 Communication and understanding one year after diagnosis**

By the second interview fears about recurrence had become a challenge for many participants. Efforts on the part of health professionals to communicate the likelihood of recurrence were described.

My Oncologist at (hospital) and he was saying 'Look, as far as we're concerned, you've had cancer, you've had surgery for cancer, you've had treatment for cancer and, as far as we're concerned, you're cancer free, so that's how we see it.' —Stephanie, age 53, (2/2)

In Philippa's case what appeared to be efforts to reassure backfired.

When I saw him again this year he said 'Oh any problems usually show up within the first two years after surgery, so you're halfway there' which I found a little disconcerting, quite frankly. And it didn't mean that he was looking to find tumours—I know it didn't. —Philippa, age 64, (2/2)

More advice on diet, immediately post-op and in the longer term would have been welcomed by participants. Sometimes specialist nurses advised people to figure out what they could and couldn't tolerate through a process of 'trial and error', and some provided an information sheet which described a bland diet, low in fibre, but participants would have appreciated more detailed guidance. Berta would have liked to have seen a dietician.

I would have liked that they give me, and after this operation, give me more advice, for example, a diet because they say 'Oh yes don't eat peas, don't eat sugar, salt' and all that stuff, you know. But it would be good for a person who suffer from bowel cancer, you know, what would be the easier things to eat, you know, probably a dietician could advise more, you know, because in here they don't say anything. —Berta, age 50, (2/2)

I don't see what else I can do. I really don't—and I have asked for help and nobody really seems to know what to do. It seems to be a food intolerance thing, I think there is an allergy to certain foods but it's the food intolerance mainly and that will not get better, I don't think. —Philippa, age 64, (2/2)

### **6.6.6 Satisfaction with secondary care one year after diagnosis**

As had been the case at first interview participants viewed secondary care as expert in colorectal cancer and were therefore the preferred source of advice for cancer related issues.

The back-up team at (hospital)—they've been very, very good. Any medical kind of question you've got, they are the people 'cause your GP doesn't really know. —Stephanie, age 53, (2/2)

The number of years that they've been doing it—they must have heard every question in the book from patients so, for me it was a great source of information. —Andrew, age 55, (2/2)

Clive continued to wonder about the potential for GP services to be expanded and he would have preferred not to have to visit hospital.

When you see the size of these clinics in the likes of the (hospital) and stuff, you just it's cattle market stuff, you know, and it must put a lot of people off—it certainly horrifies me. It's em, like, well, it's—that's what it's like in the Soviet—you know, what you imagine the Soviet system would be like. —Clive, age 59, (2/2)

I just wonder, you know, I mean, to travel away out there and does it really need to have a Consultant. I mean eh maybe some of his or her medical staff could undertake that-or indeed GPs, for that matter. — Clive, age 59, (2/2)

## 6.7 Chapter summary

The central role of GPs in the diagnostic process was appreciated by participants although there were cases where GPs were blamed for perceived delays in obtaining diagnosis. Participants often expected GPs to visit after they had been discharged from hospital following surgery for colorectal cancer and in some cases GPs did visit and offered their support. Failure to visit sometimes lead to disappointment on the part of the participants who felt the magnitude of their experience had not been acknowledged.

The 'diagnostic consultation' was remembered in detail. However, participants often learnt of their diagnosis during investigations and often in sub-optimal situations. Throughout the time of diagnosis and treatment CNSs were valued for their expertise, accessibility and for the emotional support they provided.

Participants believed they understood their illness and treatment well and attributed that to the efforts of health professionals. In spite of feeling well informed about their illness, participants preferred health professionals to make decisions regarding treatment. Plans for follow-up care had not been made clear to participants.

When participants needed to consult about issues related to colorectal cancer they favoured advice from secondary care as they believed it to be more expert.

One year after diagnosis contact with health care, especially for matters regarding colorectal cancer, was significantly reduced. Dissatisfaction with primary care dating from problems with diagnosis persisted. The expertise of secondary care, accessed at follow up appointments, was valued.



## **7 Discussion**

### **7.1 Introduction**

This discussion begins with a methodological critique that reflects on the longitudinal design and by considering the strength of evidence which can be claimed. Then the main body of the discussion concentrates on a key concept that has emerged during the research process: uncertainty. Next, literature on uncertainty in illness is considered in order to give the notion of uncertainty context. A synthesis of the findings is then detailed using suggested categories of uncertainty as a theoretical lens. The chapter concludes with recommendations and practice implications.

### **7.2 Methodological critique**

This section considers the longitudinal design, the strengths and limitations of the study, the experience of being part of the PICT study, and the researcher influence on the data collected.

#### **7.2.1 Longitudinal design**

Of the qualitative papers investigating the experience of colorectal cancer only Beech, Arber and Faithfull, (2012) and Hubbard, Kidd and Kearney (2010) incorporated a longitudinal design by interviewing participants more than once. It is a strength of this work that it contributes to a relatively small body of longitudinal work on the experience of colorectal cancer.

The longitudinal study design allows exploration of differences and similarities of the experience at diagnosis and one year and identification of transient or enduring aspects. A number of the findings in this work could only have been revealed by a longitudinal design:

- Participants are unprepared for the enduring nature of physical symptoms such as bowel dysfunction, sexual problems and fatigue. This contracts

with their experience of treatment when they had felt well informed about what to expect.

- Participants face enduring psychological struggles one year after diagnosis, most notably living with the fear of recurrence.
- Participants were unlikely to seek support for enduring issues associated with colorectal cancer, either psychological or physical, one year after diagnosis.
- Although a return to 'normal life' may be possible effort and ingenuity are required, for example, to manage ongoing bowel dysfunction in a social context.

### **7.2.2 Reflections on the methods**

It is a strength of the study is that the student does not have a clinical background and brought less of a bias to the interviews than a clinician with knowledge and experience of caring for colorectal cancer patients might have done.

However, there are constraints that limit the strength of evidence this work can offer. First, five participants were lost to the second interview. Two had died, two were no longer contactable and one was too ill to take part in an interview. The stories of these five might have tempered the tone of the findings. The longitudinal design unavoidably favours those enjoying better trajectories. The less fortunate course which colorectal cancer can take is missing from this work.

Second, there may have been selection bias by the CNSs who made the initial approach to patients in favour of patients whom they were more involved with. CNSs may not have asked those who they deemed too ill to take part so those with poorer prognosis may not have been included. However, participants for this qualitative work were recruited using a sampling frame which ensured maximum variation in age, sex, socio-economic status and level of co-existing morbidity and monitored for stage of cancer thereby minimising the potential for bias. (As with all qualitative work the sample is not designed to be

representative and therefore the findings cannot be generalised to all colorectal cancer patients.)

Third, there are features of an exclusively Glasgow based sample that may impact the findings. The issues of access to health care faced by rural populations are not experienced by this urban population and the relatively positive picture of the experience may be in part due to a stoical and uncomplaining attitude which is a cultural norm particularly among older Glaswegians.

An additional observation regarding methods which may have some significance for the findings is that: although three hospitals were involved in recruitment and the request had been for consecutive recruitment, one hospital recruited a significantly (pro rata) greater number of patients. The CNS who recruited from this hospital was particularly valued by her patients and it is possible that her particularly patient-centred approach is reflected in these findings.

### **7.2.3 Reflections on being part of the PICT study**

Being part of a larger study offered both benefits and drawbacks. Benefits included the expertise and experience of the larger team. Regular study team meetings afforded the opportunity to share experiences of fieldwork and discuss the progress of the study. Colleagues were helpful with queries about colorectal cancer and about the methods we were using and shared any relevant literature they came across.

However having to carry out a researcher administered questionnaire proved to be a drawback to the qualitative work. Because participants had originally taken part in the researcher-administered questionnaire survey for the PICT study it was possible to gauge which participants from the PICT study could contribute most to the qualitative work in terms of their willingness to talk in-depth about their experience. Only those who demonstrated a willingness to talk were asked to take part in the qualitative study. In some cases they seemed less willing to converse in the same detail when they were interviewed for the qualitative work. Possibly the presence of recording equipment was off-putting but it seems more likely that they had told their story at the first meeting and retelling the

story a second time was a wearisome endeavour. A degree of detail may have been lost in this second telling.

#### **7.2.4 Researcher Influence**

Reflexivity should be considered in the process of data collection and analysis in qualitative work.

Social researchers should be reflective about the implications of their methods, values, biases, and decisions for the knowledge of the social world they generate. Relatedly, reflexivity entails a sensitivity to the researcher's cultural, political and social context. (Bryman, 2004, p 500).

The data collected in an interview will be influenced by the experiences and values of the interviewer and the interviewee. The interview is a form of social interaction that may be not be an equal interaction.

Cornwell (1984) says the academic researcher can be perceived by participants as having an authoritative role, which may impact the interview interaction, specifically, it may make participants provide an account they believe to be acceptable.

The participants may have viewed me as a University researcher with a degree of authority and their responses may have been influenced by this. For example, participants may have given responses they thought I wanted to hear, especially in relation to their thoughts on health care professionals.

However, my hope was that participants would not see me as a person in authority and that they would feel comfortable and we could establish a rapport. Rapport was easy to establish with the younger female participants because of the similarity in age and gender. However, the majority of participants were significantly older than me and men were included in the research.

I used a number of strategies in order to try and establish rapport. First, I always pointed out that I was not a health professional. Second, I was dressed relatively casually. Third, I dispensed with the paper copy of the interview schedule so that a more natural conversational style could be achieved and I could maintain better eye contact.

Additionally, as an experienced interviewer I was able to demonstrate a familiarity with the healthcare systems the participants were engaging with and to remain unfazed when they talked about upsetting or frightening experiences.

As the fieldwork progressed the quality of data generated improved and this is likely to be attributable to firstly, my increasing confidence with the interview schedule and secondly, a repertoire of prompts I acquired as I became familiar with the range of participants' experiences.

Participants appeared comfortable talking their experiences and did not avoid revealing the difficult aspects of their experiences. When participants did become upset I offered to switch the recording equipment off but usually participants preferred to continue talking. In these cases I made sure that there was sufficient conversation after the interview to lift the mood.

### **7.3 Reflections on the aim of the study**

The overall aim of the study is to explore the physical, social and psychological impact of colorectal cancer at diagnosis and one year post diagnosis, with a particular focus on the impact of health care professionals on patients' experience.

The findings suggest that colorectal cancer is experienced most acutely psychosocially. The central characteristic of the psychosocial experience is uncertainty. Health care professionals at times mitigate, and at times exacerbate, the experience of uncertainty.

In this study, uncertainty was found to be a major presence at all stages in the participants' experience. The literature on the patient experience of colorectal cancer can also be interpreted as having uncertainty as a central theme.

In the following section the concept of uncertainty in illness generally, and in cancer specifically, is introduced. Then four categories of uncertainty, based on the uncertainties described in this study, are suggested. These categories are then used as an organising concept with which to present a synthesis of the findings and to consider the literature.

## **7.4 Describing uncertainty**

Uncertainty is a multi dimensional concept (Shaha et al., 2008): which varies over time (Northouse, et al., 2000) and is experienced not only by the patient, but also by their wider circle of family and friends.

How and to what degree, uncertainty changes overtime has not been investigated (Shaha et al., 2008) but it is a feature of the cancer experience beginning early on with symptoms (Mishel, 1988) and persisting long after the completion of treatment (Miller, 2012).

The patient's partner, family and friends also experience uncertainty and have information needs (Shaha et al., 2008), indeed, the partners of cancer patients experience similar levels of distress and uncertainty as the patient (Gilbar and Ben-Zur, 2002). Hagedoorn et al., (2008) suggest that the partner's uncertainty affects the patient's well-being.

The idea that uncertainty is a feature of the illness experience generally was originally proposed by Mishel (1998). Mishel's uncertainty in illness theory (Mishel, 1988; Mishel, 1999) states that many features of illness may promote uncertainty, including diagnoses and prognoses, treatment plans, and unfamiliar symptoms. Mishel notes that uncertainty starts early in the experience and is particularly upsetting for people who do not have a diagnosis (Mishel, 1988).

Mishel developed two related theories of uncertainty. Her original theory is concerned with the diagnosis and treatment phase, while the reconceptualisation of this theory focuses on the experience of illness after diagnosis and treatment, and considers how uncertainty is integrated into people's lives as they adapt to life with chronic illness (Mishel, 1990). Mishel draws on chaos theory, specifically the idea that phenomena become

repatterned, to suggest that people who live with continual uncertainty find a way to accommodate it (because it is impossible to dismiss or ignore).

Mishel contends that uncertainty can be viewed as an opportunity as well as a threat. Uncertainty is an opportunity for hope when certainty about a prognosis may be distressing. Uncertain illness events are considered opportunities when positive outcomes are expected and as threats when the expectation is for a negative outcome. Additionally, in accepting uncertainty new thought processes evolve whereby uncertainties can offer increased freedom. Mishel's work questions assumptions that the experience of uncertainty is universally negative.

Miller (2012) draws on Mishel's concept of uncertainty and investigates the experience of uncertainty in cancer for both cancer survivors and their partners. She borrows her categories of uncertainty from Brashers et al.'s (2003) work about uncertainty in the experience of HIV patients (Miller, 2012) and suggests three sources of uncertainty that persist throughout survivorship: medical, personal, and social. Medical sources of uncertainty include the cancer diagnosis, treatment and prognosis. Personal sources of uncertainty include conflicting identities and questions about employment. Social sources of uncertainty include questions about disclosing the diagnosis and the effect of the illness on relationships.

While Miller's work is helpful in applying general theories of uncertainty specifically to cancer and highlighting uncertainty as a survivorship issue, her categorisation of sources of uncertainty fails to differentiate between aspects of uncertainty associated with the illness and aspects associated with treatment. Separating uncertainties related to the illness and treatment could assist future efforts to address uncertainties. Miller's work fails to offer any hierarchy of uncertainties, however in this study thoughts about the prospect of death are evident at all stages of the journey and appear to be consuming suggesting that existential fears trump all other uncertainties.

A review of the literature on uncertainty for breast, prostate, and colorectal cancer patients concluded that there is least research on how colorectal cancer patients cope with uncertainty (Shaha et al., 2008).

The data in this thesis offer the opportunity to describe the uncertainties and coping mechanisms of colorectal patients and the ways in which health care professionals exacerbate or ameliorate patients experience of uncertainty.

The uncertainties described in this study have been ordered into four categories.

Cancer is understood to be fatal (Schulte, 2002) and so all cancer patients experience uncertainty about their long term future (Mishel, et al. 2002). These uncertainties can be described as existential uncertainties.

Existential uncertainties may begin before diagnosis if cancer is suspected. They include confrontations with the prospect of dying during the diagnostic and treatment phases and fear of recurrence after treatment. Existential uncertainty can result in the patient feeling changed and these changes may be similar to the notion of biographical disruption.

Biological uncertainties depend on the illness itself. Questions arise about the biology of the illness, for example, the stage or spread of cancer, which relate to the likelihood of it being curable.

Medical uncertainties are associated with the diagnostic process, treatment and care. These uncertainties may arise from deficient information or suboptimal communication between the patient and health professionals and include uncertainties about treatment decisions, treatment outcomes and treatment side effects.

Social uncertainties describe the uncertainties that arise in the patient's social world as a result of the illness and treatment. Rozmovitz and Ziebland (2004) detail the way in which an adult social world which usually includes work, social lives and sexual lives and is characterised by dignity, privacy and independence, is no longer certain for those with colorectal cancer.

## **7.5 The experience of uncertainty in three phases**

The findings in this study demonstrate that uncertainty proves profoundly unsettling (in spite of efforts to interpret the experience positively). Patients'



experiences occupy three distinct phases: up to diagnosis, between diagnosis and treatment, and after treatment. The following sections summarise each phase using the idea that uncertainty can be categorised under four main headings: existential, biological, medical, and social.

### **7.5.1 Phase 1 - to diagnosis**

In the time leading up to diagnosis symptoms are identified and health professionals consulted. At this early stage experiences are often described using the language of uncertainty.

The physical experience in this first phase is often unremarkable with the initial symptoms of colorectal cancer being vague and mild. By contrast the psychological experience is profound. In this first phase existential uncertainties focus principally on whether the diagnosis is cancer. Patients face the uncertainties inherent in a diagnostic process until a firm diagnosis can be made. Uncertainty is insidious for people who do not have a diagnosis but who suspect cancer because of their own knowledge of symptoms. Symptoms and their cause are the focus of biological uncertainties.

A diagnosis of colorectal cancer is shocking because it renders the patient's future uncertain and causes patients to face uncertainties about their survival. In spite of the shock patients respond calmly and sometimes feel relieved. That patients may feel relieved on learning they have cancer indicates the powerful negative effects of waiting for a diagnosis.

Medical uncertainties arise when GPs are uncertain of the cause of symptoms. GPs are patients' first point of contact with the health service in the lead-up to diagnosis. Usually the route to diagnosis is speedy and straightforward. However, GP uncertainty is evident when participants are treated for something else, and to a greater extent, when the response of the GP to symptoms is perceived as slow, giving rise to significant dissatisfaction.

## 7.5.2 Phase 2 - diagnosis and treatment

Diagnosis and treatment comprise the ‘main events’ in the cancer journey, and many uncertainties occur during this time.

These uncertainties may occur in the context of the patient feeling physically unwell, as a consequence of treatment (most notably during and immediately after their hospital experience). Physical problems after surgery are: bowel dysfunction; pain; weight loss; wounds not healing and sexual issues.

The uncertainties that emerge with a firm diagnosis are existential uncertainties as the patient confronts their mortality and wonders if their diagnosis will prove terminal.

These high level existential uncertainties give rise to biological uncertainties: questions about the biology of the illness, the answers to which could inform the bigger concerns about survival. The patient wonders about possible causes, whether they are to blame, if the diagnosis of cancer is correct and applicable to them, if the cancer will be treatable and if it has spread to other parts of the body (making it more difficult to treat successfully).

Patients find their own ways of adjusting to uncertainty such as: discussing worries or blocking out the possibility of bad outcomes; drawing on faith; taking on positive attitudes and looking for positive interpretations of their experience.

However, the experience of uncertainty may be exacerbated by a number of medical uncertainties to do with treatment and care. The patient is uncertain about the role of health professionals, and in particular is unclear about what the GP’s contribution is and whether the GP will visit or call after a hospital stay. Some GPs do contact patients on their return from hospital and some patients clearly expect this contact after discharge but there is no uniformity of practice. After the patient is discharged the GP’s role includes dealing with a small number of cancer-related medical issues but more frequently with medical issues which are not cancer-related. Overall satisfaction with GPs is high and any dissatisfaction is related to a perceived delay in diagnosis or stems from a previous dissatisfaction.

During this phase nursing care in the community is usually concerned with wound management but often incidentally includes psychosocial support. Patients seldom seek psychosocial support from GPs and wonder whether they can consult a GP or CNS with non cancer concerns. CNSs are greatly valued for their expertise, accessibility and provision of emotional support. Stoma nurses are similarly valued and surgeons are held in very high regard.

Patients are cared for primarily in secondary care during this phase and express some concern that primary care lacks expertise in colorectal cancer although there are indications that communication between primary and secondary care works well.

The consultation where the patient learns of their diagnosis is clearly remembered. The patient may suspect they have a cancer diagnosis before this consultation because of the behaviour of health professionals. Patients who are told during investigations that cancer is suspected may be unclear about whether the 'suspicion' constitutes a diagnosis. The treatment plan is outlined early on and this, along with the speed of treatment, gives the patient confidence that the cancer is treatable and mitigates uncertainty.

The patient appreciates the efforts of health professionals to communicate with them although communication around diagnosis may be unclear. Uncertainty can arise when medical terminology is used, for example, conversations about lymph nodes are confusing to the patient who does not understand their significance. Health professionals' attempts to reassure by communicating the likelihood of recurrence can backfire.

Additional medical anxieties are experienced around investigations and treatment. For example, the patient may not know: whether surgery will be open or laparoscopic; whether there will be complications from surgery; whether or not they will require a stoma; if adjuvant treatment will be required; and during chemotherapy if each blood test result allows the scheduled chemotherapy to proceed. Hospital stays are shorter than expected but sometimes sub-standard care is reported. There is a great deal of uncertainty around what plans for follow-up entail. Ultimately, the patient does not know whether the treatment will successfully eradicate the cancer.

The health professionals' own uncertainty is evident during treatment when clinicians offer different opinions regarding whether adjuvant chemotherapy is required and when the doctor unwittingly exacerbates the patient's uncertainty by asking the patient to contribute to decisions about treatment.

Uncertainty cascades to the various social spheres of the patient's life: to relationships and families; to employment; to finances; and to social lives.

Thoughts about the implications of what could be a terminal diagnosis centre on concerns about family, particularly children. Efforts are made to hide the psychological struggles with existential uncertainty from family and friends. Patients wonder about their capacity to care for others and when that capacity is compromised they feel distressed. There is ambiguity about the potential for sexual relationships to be resumed in the future.

The ability to function in a work environment (especially for younger patients) is called into question, for indeterminable lengths of time. Patients are very keen to return to work, due to work's centrality to 'normal life' but they question whether physical symptoms can be managed in a work context. Domestic work proves difficult and patients manage with help from spouses and others, by 'letting things go' and using services such as online shopping.

Those in employment worry about the impact of the illness on their finances and seem unclear about the extent of sickness pay. Finances are uncertain because of the issues regarding employment but also because patients do not know whether they are eligible for benefits or how to apply for benefits. Patients do not know whether they can pay their bills on reduced incomes.

Patients are unsure whether social care is desirable and whether they would have to pay for it.

Social lives are put on hold during this phase but looking forward patients wonder if bowel dysfunction will prevent socialising and travel. They are unsure what foods they should be eating at this point to avoid pain and discomfort.

Planned holidays are cancelled or postponed for treatment and recovery. Later, making plans for much needed holidays may not be possible in the context of uncertain health and uncertain treatment regimes and because of uncertainties about eligibility for affordable travel insurance. The particular uncertainties associated with adjuvant chemotherapy serve to make planning social lives and holidays particularly difficult for extended periods of time.

### **7.5.3 Phase 3 - after treatment**

The third phase begins as treatment is complete and includes a follow-up schedule which will span five years, beginning another cycle of uncertainty.

The patient may be pleased with their health and cope well with a stoma or they may experience a range of physical symptoms. Physical symptoms may be: fatigue; bowel dysfunction; sexual dysfunction; hernias at the site of wounds; weight gain; anxieties; chemotherapy; and radiotherapy side effects and late effects. The physical symptoms of the illness and treatment, experienced during the second phase, are challenging but they are expected and understood. By contrast, physical symptoms which persist a long time after the completion of treatment are unexpected and confusing.

Surviving the period of diagnosis and treatment does not mean that existential uncertainties are left behind. Rather that these uncertainties become a feature of patients' lives, to varying degrees across time and between patients. The existential fear with which the patient lives is the fear of recurrence.

Psychological well being is compromised by existential uncertainties and the patient feels emotional, anxious and experiences low moods. After a year to reflect on their experience, patients talked more about the psychological experience of their illness than they had done during the treatment phase. A range of psychological experiences are described and some patients may consider their experience to be in the past while for others it may still be current and difficult.

The patient remains uncertain how to comprehend their diagnosis and reconcile their existential fears. They describe a year in which they have invested effort in

assimilating their experience as it relates to others and understanding how their story might play out by finding parallels and differences with others. They judge themselves and others as good (or not) patients and may infer that being a 'good patient' will affect their outcome.

The experience of uncertainty, most notably the experience of existential uncertainty, leads to the patient feeling 'changed'. Patients say they have: changed perspectives; changed values; improved priorities; value life; live for the moment; value time; feel grateful and appreciative; and do things they might not have done previously. Additionally, patients claim a greater readiness to consult with symptoms.

Existential uncertainties at this stage are still rooted in biological uncertainties but now they are based on the question of recurrence. Pain triggers fears about recurrence because it could signal the return of cancer.

Lower level biological uncertainties which occur at this point include surprise to be enduring the physical effects of treatment such as bowel disturbance, pain, and sexual problems so long after the illness episode. The patient may be uncertain about whether these effects are temporary or permanent, and whether they are normal or not. Age is a confounding factor and patients do not know if poorer health is to do with age or cancer. Patients continue to think about the cause of their illness and wonder if there had been clues, mild symptoms, of the cancer long before they presented to their doctor.

Treatment is complete and the associated medical uncertainties are in the past. The patient now speaks much less about health care, reflecting its reduced significance in their lives. However the patient is enrolled in a follow-up regime which brings with it new medical uncertainties. The details of the regime are unclear and follow-up visits trigger fears about recurrence because the patient understands follow-up is intended to detect recurrence.

In this phase patients report little contact with their GPs, particularly regarding colorectal cancer. Contact with health care is primarily contact with secondary care at follow-up appointments. Although this contact involves the challenge of coping with the rising level of fear of recurrence, participants continue to

express satisfaction and confidence in secondary care health professionals. As was the case in the second phase, patients do not seek psychological support in spite of their psychological struggles.

Again, uncertainty is experienced in social lives but the degree of this is greatly reduced in this third phase.

Employers are supportive and the return to work is phased. Work remains central to normal life although ongoing physical issues sometimes make work difficult and the patient wonders if physical late and long-term effects can be managed in a work environment and if they will improve in time. Benefits sometimes prove difficult to obtain but when they are obtained they make life easier. Domestic chores have been resumed. Holidays are taken to mark the end of treatment.

Social lives have been resumed although bowel issues can make socialising difficult. Alterations have been made to diets because of bowel sensitivity but also in the hope of warding off a recurrence.

## **7.6 Uncertainties in the context of the literature**

The categories of existential, biological, medical and social uncertainty allow the experience of colorectal cancer including the contribution of health professionals described in this study to be captured.

In the following section the same four categories of uncertainty are used to order a comparison of this study with the literature and to consider the extent to which the idea of uncertainty is present in previous qualitative work.

### **7.6.1 Existential uncertainty in the context of the literature**

Three of the four studies described in chapter two as contending that biographical disruption is central to the experience of colorectal cancer have existential uncertainty at the core of their thinking.

Uncertainty is a key feature of Little, et al.'s (1998) liminal state (which replaces the pre diagnosis identity). Little, et al. recognise the uncertainties the patient experiences about future available time.

Hubbard, Kidd and Kearney's (2010) work on biographical relies heavily on notions of existential uncertainty. They draw on Bury's concept of biographical disruption in chronic illness in which pain and death become relevant as the certainty of a future evaporates. To understand Bury's coping mechanisms, specifically bracketing, in terms of uncertainty means that the individual works to maintain a sense of self in the face of uncertainty. For example, not thinking about illness in a work environment is bracketing the idea of an uncertain future by focusing on the certainties of daily work.

Central to Hubbard, Kidd and Kearney's (2010) contribution is the idea that biographical disruption may or may not occur. Their version of biographical disruption is more nuanced than that of other authors because biographical disruption is not universally applicable and also because it may be temporary or permanent. Stage of life or a hard life (meaning the experience of multiple chronic illnesses) may reduce the likelihood of biographical disruption. It is plausible that older people or those already living with chronic illness have already been disabused of the certainty of a long life.

Beech, Arber and Faithfull (2012) also contend that a diagnosis of colorectal cancer means that the 'future is uncertain'. Their focus on recovery can be interpreted as an attempt to reinstate what is certain: the 'restored self' judges the illness to be in the past. Indeed, it is uncertainty about the future, most evident in fears of recurrence, that means 'a sense of illness' dominates 'a sense of wellness' and thwarts recovery.

Miller's (2012) work on uncertainty in cancer does not address the idea of biographical disruption but she does describe 'conflicting identities', a notion similar to biographical disruption, as a personal source of uncertainty. Conflicting identities occur when patients struggle to reconcile their identity as a cancer patient or as a cancer survivor, or when their sense of themselves is challenged because of changed physical appearances.



Little, et al. (1998) claim that a cancer diagnosis changes the patient's identity permanently: they are a cancer patient (regardless of time since diagnosis or whether or not there has been a recurrence). Their previous life is unavailable to them now as they are permanently changed and live in a state of suspended liminality where they construct and reconstruct the meaning of their experience by means of a narrative. Ohlsson-Nevo, also depicts a permanent change in the title of her paper 'Life is back to normal and yet not': normality has been resumed but it is a new normality because 'life has a shadow of death'.

Patients adjust to existential uncertainty through a range of strategies including: avoidance; denial; fighting spirit; positive optimism; and hope (Shaha and Cox, 2003). They regain the locus of control, lost during the treatment phase while submitting to the health care regime, by deferring less to health professionals and seeking information (Shaha et al., 2008).

Patients may interpret the experience of living with existential uncertainty as positive. Mishel (1990) introduced the counterintuitive idea that uncertainty can lead to outcomes which may be considered positive. Ohlsson-Nevo, et al. (2012) describe the year from diagnosis as difficult, but it is also viewed as a positive, enriching experience. This interpretation of being changed in a positive way resonates with the findings described here. The aspects of feeling changed which are described in this study, e.g. valuing life, valuing time, and living for the moment are positive interpretations of living with existential uncertainty.

In summary, biographical disruption is a fundamental change to the individual's sense of self, arising from a sense of available time as limited. The changes associated with existential uncertainty described by participants in this study suggest an overlap between the notion of biographical disruption and the effect of living with existential uncertainty.

### **7.6.2 Biological uncertainty in the context of the literature**

The findings in this study suggest that patients are concerned with questions about the biology of their illness however these concerns are generally not reflected in the literature.

Miller (2012) describes disease-related uncertainties such as ambiguous symptoms and categorises these alongside treatment uncertainties under the heading of 'medical sources of uncertainty'. Elsewhere the biological uncertainties are inferred as information gaps about the illness are identified e.g. patients receive inadequate information about the illness and prognosis (Shaha et al., 2008).

### **7.6.3 Medical uncertainty in the context of the literature**

The central place of healthcare in the experience of colorectal cancer is not generally reflected in the literature. Some attention is paid to information provision and treatment uncertainties.

Uncertainty is triggered by poor information provision (Shaha et al., 2008). Deficient information is raised as an issue by a number of studies. Patients receive inadequate information about treatment (Shaha et al., 2008) and information about treatment options is contradictory and incomplete (Bain, et al. 2002). Where patients do not see a CNS they are likely to miss information (Worster and Holmes, 2008). The findings in this study suggest that patients are satisfied with information provision in the diagnosis and treatment phase suggesting that improvements in information provision may have occurred.

After treatment is complete the fear of recurrence is not addressed by current information provision (Northouse, et al. 1999) and uncertainty is reinforced by regular screenings Shaha, et al. (2008). These findings are borne out in this study suggesting that there may be issues with information gaps about the long term management of the disease.

### **7.6.4 Social uncertainty in the context of the literature**

According to Rozmovits and Ziebland (2004) the patient experiences multiple uncertainties in their social world when uncertain bowel control diminishes their capacity to take part in society. Ohlsson-Nevo, et al. (2012) point out that the patient desires a return to their normal life and their usual social world and this may be a mechanism for coping with existential uncertainties.

Patients' ability to work, socialise, travel and continue their usual domestic regimes is compromised (Rozmovits and Ziebland, 2004). Certainty in bodily control is a requirement of adulthood as defined by the theorists, Douglas, Elias and Lawton, underpinning the work of Rozmovits and Ziebland (2004). Societal expectations of control of bodily functions cannot be met when bowel control is uncertain and, by extension, the individual's role as an adult is made uncertain (Douglas, 1982, 1985). For Elias (1939) the civilised individual has control of his body and bodily functions. Thus, uncertainty regarding bodily functions compromises the role of the civilised individual in a civilised society. Lawton (1998) claims a requirement of a place in society is a body that functions in compliance with social norms: such compliance would involve certainty of control of bowel function. In Rozmovits and Ziebland's (2004) research the lack of bodily control, which is exemplified most acutely in the experience of life with a stoma, renders the patient socially incompetent and prevents them engaging with work, social and sex lives.

In the same way that existential uncertainties can lead to 'feeling changed', so too can restrictions to the patient's social capacity result in change. Rozmovitz and Ziebland (2004) say that people recall alienation, even when their normal life had been resumed, because of a heightened awareness of the physical/social body relationship.

However, the interpretation of compromised bowel function and life with a stoma as disrupting the patient's social world, and therefore their identity, does not resonate with the findings in this thesis. Worster and Holmes (2008) assert that colorectal cancer patients are more preoccupied with the idea that they have cancer than with bowel disease. The findings in this study point to existential uncertainties as the force behind changes to patients' sense of themselves rather than changes to bowel function and the experience of life with a stoma causing spoiled identities.

That the experience of colorectal cancer appears to be less defined by the experience of having a stoma in this study than in Rozmovitz and Ziebland's (2004) work may reflect the reduction in the number of colorectal cancer patients requiring a stoma due to advances in surgical techniques. This study has a lower proportion of participants with a stoma: only five (of 24) participants

had experience of a stoma contrasting sharply with Rozmovitz and Ziebland's (2004) study where 22 of 39 participants had a stoma.

Differences in the weight accorded to life with a stoma may also reflect improvements in stoma care. In this study the accounts of those with experience of stoma (either temporary or permanent) suggest that, although a stoma may require effort to learn to manage, it does not prevent the resumption of a normal life.

The theme of 'normal lives' as described in qualitative studies (Shaha et al., 2008; Ohlsson-Nevo, et al., 2012) can also be understood within the context of social uncertainty. Normal lives are what we know for certain and to resume them is to regain some certainty (of what our lives are). The idea of continuing lives as normal is understood as a psychological coping mechanism by Ohlsson-Nevo, et al. (2012), who contends patients manage the physical and emotional impact of colorectal cancer so that their normal lives are preserved as far as possible. In this study the desire to resume normal lives is most evident from participants' wishes to return to work.

### **7.6.5 Where uncertainty does not accommodate the findings**

While the majority of the experience of colorectal cancer at diagnosis and one year later can be explained in terms of coping with uncertainty, there are aspects of the experience which cannot be categorised in this way. For example, the act of enduring physical symptoms is not an uncertainty.

The preoccupation in the previous qualitative literature, and from the present findings, is with the psychosocial experience rather than the physical symptoms experienced by the patients. However, it should be noted that while this reflects the magnitude of the psychosocial impact, it should not be taken as implying an insignificant physical experience.

In this study, bowel dysfunction and fatigue may be experienced as physical symptoms in all three phases of the experience. The qualitative literature is largely concerned with the period of diagnosis and treatment and describes the physical challenges of these phases (Sahay, Gray and Fitch, 2000). Work on

survivorship is often not cancer site-specific however it does frequently include colorectal cancer patients amongst its samples and therefore picks up the enduring nature of some physical issues such as bowel dysfunction (Denlinger and Barsevick 2009; Khan, et al., 2011; Sisler, et al., 2012). The unexpectedness of the long term and late effects of colorectal cancer, however, is not reflected in either qualitative or survivorship work.

## **7.7 The utility of biographical disruption and uncertainty as concepts**

### **7.7.1 The utility of biographical disruption**

In the previous section an overlap between biographical disruption and the effects of existential uncertainty is suggested. In the section that follows biographical disruption and uncertainty are considered for their utility in understanding the experience of colorectal cancer.

The authors who believe that biographical disruption defines the experience of colorectal cancer claim it offers an alternative to the medical model of illness which focus on the disease independent of the patient and their situation. They each contend that their understanding of the illness offers a superior model which could facilitate better support for patients.

Little, et al. (1998) argue that the concept of liminality reflects accurately the subjective experience of the illness and may therefore offer health professionals an education instrument to improve communication between health professional and patients.

Rozmovits and Ziebland (2004) assert that an appreciation of the loss of adult identity will facilitate improved advice and support appropriate to the distress caused by colorectal cancer.

Hubbard, Kidd and Kearney (2010) believe that allowing health professionals to consider the patient's biography leads to better management of the psychosocial effects of the diagnosis.

Beech, Arber and Faithfull (2012) claim that their model of recovery, which assumes a disrupted identity as its basis, offers nurses a model on which to base their support to patients as they progress towards a sense of wellness.

### **7.7.2 The utility of uncertainty**

The utility of understanding that the experience of colorectal cancer is characterised by uncertainty is twofold. First, uncertainty, unlike the terms 'biographical disruption', 'disrupted identity' and 'liminality' is an accessible term. Second, like the theories based on biographical disruption, it offers a framework for health professionals to understand the subjective experience and thereby offer appropriate psychosocial support.

The accessibility of a concept is crucial if the aim is to facilitate an improved understanding by health professionals of the patients situation. Uncertainty is a concept that uses accessible language. While there is scope for health professionals to investigate the notion of uncertainty in depth it can be understood usefully on a relatively superficial level. Colorectal cancer patients come into contact with a wide range of health professionals throughout their journey and it may be impractical to expect even a proportion of these to become familiar with the idea of biographical disruption.

The concept of uncertainty, like biographical disruption, offers an alternative to the medical model of illness which focuses on the disease rather than the patient and their individual circumstances. To appreciate that the experience of colorectal cancer involves serial uncertainties is to move beyond a medical model and understand the subjective experience.

## **7.8 Avoidable and unavoidable uncertainty**

While the experience of uncertainty cannot be eliminated there are aspects of uncertainty, particularly those that arise as a consequence of the actions of health professionals, that can be avoided. The remaining unavoidable aspects of uncertainty will then require attention with regard to how patients can be best equipped to cope. In this regard uncertainty offers a useful way of identifying scope to improve the psychosocial experience.

Health professionals may contribute to the patient's uncertainty in ways which could be avoided. The time to diagnosis is characterised by uncertainty and this is compounded if the patient perceives that the diagnosis is unnecessarily slow. Imparting a diagnosis during investigations may introduce existential uncertainty in a context that does not offer appropriate support to the patient. Patients may perceive requests for input to treatment decisions as evidence of the clinician's uncertainty.

The experience of colorectal cancer includes uncertainties which are unavoidable. A diagnosis of cancer necessarily involves the introduction of existential uncertainties. Some medical uncertainties, for example whether or not a stoma is required, may be inherent in the treatment phase. Later, the fear of recurrence is the primary uncertainty of survivorship.

## **7.9 Recommendations**

This study differs from other qualitative research on the patient experience of colorectal cancer in that it offers a) a longitudinal perspective and b) an insight into the experience of health care. These two strands allow identification of the impact on patients of the strengths and deficiencies of current health care provision from before diagnosis, through treatment and into the survivorship phase. The recommendations suggest ways of eliminating avoidable uncertainty and supporting patients to cope with unavoidable uncertainty.

Patients require two types of support in order to cope with uncertainty. They require support that is knowledge driven and support that is empathy driven. Additionally, health care systems can help to mitigate uncertainty.

### **7.9.1 Knowledge driven support**

Knowledge driven support is based on health professionals sharing their knowledge of clinical evidence and best practice with patients appropriately.

Knowledge based support appears to be a strength of current health care provision however there may be potential to reduce uncertainty with additional support of this type. Health professionals can avert the potential for

dissatisfaction with diagnoses that are perceived to be protracted by discussing their approach with the patient. After diagnosis any biological uncertainties regarding the cause of cancer, the stage of cancer and its relevance to prognosis could be addressed. Early in the treatment phase the roles of the various health professionals involved in treatment and care should be made clear. The findings here suggest that efforts to inform patients about what treatment entails, including introducing them to the people and places they will encounter, are well received. Patients are satisfied with information provision during diagnosis and treatment but lack information during the survival phase. The provision of information and advice regarding: bowel function; diet; sex and intimacy; financial implications; follow up regimes; and late and long term effects should be offered.

### **7.9.2 Empathy driven support**

CNSs are valued by the participants in this study for their expertise, accessibility, continuity of care and provision of emotional support. This kind of empathetic support implies an effort on the part of the health professional to understand what the patient experiences as they attempt to make sense of their trajectory. Empathy driven support necessarily involves an appreciation of the subjective experience of the patient. The use of uncertainty as a unifying concept facilitates such an understanding.

Living with a fear of recurrence appears to be an almost universal experience of survival, yet the degree to which it affects people varies greatly. Some people experience colorectal cancer as devastating while others emerge from a straightforward illness experience relatively unscathed. Some patients require more support than others.

An empathic approach requires the health professional to appreciate that cancer occurs in a cultural context which has the effect of placing demands on cancer patients. Patients may manage uncertainty by taking on a positive outlook or by denying their diagnosis. Wilkinson and Kitzinger (2000) question the authenticity of patients' assertions of 'being positive' as an accurate description of cognitive states. Their discursive analysis of cancer patients' discussions of their diagnosis concludes that patients are responding to a prevailing understanding that they



are required to think positively in order to arrest any progression of their cancer. Therefore claims of thinking positive may mask struggles to cope.

Killoran, Schlitz and Lewis (2002) say that ‘there are two common images of cancer in popular culture: (a) the sense that a cancer diagnosis is a “death sentence” that causes some people to respond with an overwhelming sense of fear for themselves or for others and (b) the understanding that a diagnosis of cancer is transformational, ‘a second chance at living’. Each of these images is reflected in these findings. Living with a death sentence, is referred to as existential uncertainty in this study. The understanding of a diagnosis of cancer as transformational is indicated in expressions of changed priorities: of valuing life and time. The societal expectation to be transformed may get in the way of the everyday reality of cancer patienthood and survivorship.

### **7.9.3 Health care systems reducing uncertainty**

Health care can include systems that operate to reduce uncertainty, specifically: effective communication, expedient treatment, and the provision of support for the patient’s wider circle.

The findings in this study suggest that good communication from health professionals helps people handle uncertainty. While it is impossible to offer guarantees about survival, patients feel encouraged by confident interactions with health professionals and appreciate efforts to impart information clearly. Clear communication avoids the use of medical terminology and is consistent between health professionals. Health care professionals should reflect on their own uncertainties and how these are communicated to patients.

The initial existential uncertainty that arises at diagnosis appears to be somewhat mitigated by the communication of a treatment plan with intent to cure. While some may find the speed of treatment unsettling it is likely to ameliorate uncertainty.

The experience of colorectal cancer impacts on the patient’s wider circle and support from health professionals should be extended to partners, family and friends.

### **7.9.4 Comorbidity**

An additional component of the context in which the patient experiences colorectal cancer is comorbidity. Patients are more likely to experience cancer in addition to other illnesses than to experience it in isolation. Barnett, et al. (2012) highlight the proportion of patients who will have cancer in addition to other comorbidities. Just 23% will have cancer only; 21% will have cancer and one other condition; 17% will have cancer and two other conditions; and 39% will have cancer and three or more other conditions. Having a combination of illnesses may lead to poorer outcomes for patients. Macleod, et al. (2000) compared the hospital and general practice records of affluent and deprived women with early breast cancer and found that affluent women's better survival rates were not attributable to their cancer care. The authors suggest that 'poorer outcomes among these women is probably due to factors which result in deprived communities having poorer health outcomes rather than to management of their breast cancer'.

The effect on outcomes of comorbidities is missing from much research as comorbidities are frequently an exclusion criteria as researchers seek to avoid confounding factors in their results. The findings here show that comorbidities impact the psychosocial experience particularly into the survival phase when those who have had colorectal cancer in isolation resume their normal lives while those living with other illness describe ongoing limitations which may have been exacerbated by the cancer experience.

In contrast to other medical specialties, primary care is well placed and most accustomed to caring for people with more than one condition.

### **7.9.5 A central role for primary care**

These findings, considered in the light of planned reductions in specialist based care, point to opportunities for primary care to contribute more to the care of colorectal cancer patients, particularly in the survivorship phase. The findings in this study demonstrate effective communication with secondary care which should facilitate expert input.

In a publication from this thesis (Browne, et al., 2011; also Appendix 7) the issue of unmet need combined with a reluctance to identify primary care as a potential source of support was described. Patients do not currently perceive primary care as having a central role in their care. Secondary care is seen as central to the experience and CNSs in particular have a positive impact on patients' experience (because CNSs offer expertise, continuity of care, emotional support and are accessible). The attributes offered by CNSs could equally be offered by primary care but primary care's capacity to support should be communicated to the patient.

Contacting a patient after a cancer diagnosis would afford the opportunity for GPs to offer support and impart to the patient their capacity to contribute.

Many of the symptoms experienced by colorectal cancer patients, such as bowel dysfunction, sexual problems, fatigue and low mood, are routinely catered for in primary care. Additional strengths of primary care are the capacity to offer empathetic support, continuity of care, psychosocial support and manage comorbidities.

Cancer care reviews occurring at a designated appointment planned to coincide with the end of treatment offer the opportunity to: address feelings of abandonment that may occur at the end of treatment; address the uncertainties that persist into survivorship; and tailor the provision of information and support to the patient's situation.

Efforts to reduce uncertainty and support the patient through a central role for primary care are consistent with the NCSI (Department of Health, 2010) vision for survivorship care which prioritises: recovering health and well being; holistic assessment, information provision, a personalised approach; and supported self-management.

## **7.10 Future research**

The interpretation of the experience of colorectal cancer as being characterised by uncertainties raises a number of questions which suggest the need for more research.

There is potential for this research, which has begun to identify and describe uncertainty, to lead to work which may be able to measure uncertainty and intervene effectively. Such work would initially require additional investigation regarding domains of uncertainty.

In beginning to describe uncertainties this study raises a number of questions relating to the nature of uncertainty:

Is the experience of uncertainty similar across different cancers?

What strategies for coping with uncertainty are most effective and with what kinds of uncertainty?

How does communication between health professionals and patients impact on uncertainty?

What are the relationships between uncertainties e.g. do less consuming uncertainties distract from, or fuel, existential fears?

Does intervening to address uncertainty improve psychological outcomes?

Finally, as the survivorship agenda in the UK advances and changes to the configuration of care take place there will be scope to examine the impact and acceptability of such changes.

## **7.11 Conclusion**


In conclusion this study has demonstrated that the physical illness of colorectal cancer has profound implications for the patients' psychosocial wellbeing. Many of these implications can be understood as uncertainties. The uncertainties arising from the experience of colorectal cancer can be categorised as: existential (pertaining to fears of death); biological (relating to questions about the illness itself); medical (uncertainties about treatment and care); and social (regarding ambiguities that arise in the patients' social world). Uncertainty can prove deeply unsettling and existential fears can be consuming and lead to patients feeling 'changed'.

Beyond the treatment phase, a mismatch occurs between the need described by the patient and the issues about which they consult. Anxieties and uncertainties are not discussed with health professionals and, although the patients' own social networks provide crucial support, patients do not share anxieties here either, because they do not wish to burden friends and family. Patients perceive that primary care lacks expertise in colorectal cancer yet primary care routinely deals with many of the issues they face, both physical and psychosocial. Secondary care is preferred and CNSs in particular are held in high regard because they are expert, accessible and provide emotional support and continuity of care.

However, the role of secondary care for survivorship will change as specialist care is reduced. There is clear scope for primary care to cater for many of the physical, psychological and social needs of colorectal cancer. Primary care is accustomed to: supporting recovery; providing information; supporting self care; using a personalised approach; and a holistic perspective. These are all facets of the NCSI vision future for survivorship care but they would also serve to create a desirable setting in which health professionals can mitigate uncertainty.

## 8 Appendices

### 8.1 Letter of ethical approval

Multi-Centre Research Ethics Committee for Scotland	Secretariat Deaconess House 148 Pleasance Edinburgh EH8 9RS Telephone 0131 536 9026 Fax 0131 536 9346 www.corec.org.uk	
Dr Neil C Campbell Department of General Practice & Primary Care University of Aberdeen Foresterhill Health Centre Westburn Road Aberdeen AB25 2AY	Date: 30 January 2006 Your Ref.: Our Ref.: 06/MRE00/3 Enquiries to: Walter Hunter Extension: 89026 Direct Line: 0131 536 9026 Email: walter.hunter@lhb.scot.nhs.uk	
Dear Dr Campbell		
<b>Study title:</b>	<b>Establishing the potential for primary care to tackle social inequalities in established colorectal cancer</b>	
<b>REC reference:</b>	<b>06/MRE00/6</b>	
The Multi Centre Research Ethics Committee for Scotland, Committee A reviewed the above application at the meeting held on 26 January 2006.		
<b>Ethical opinion</b>		
The Committee had no ethical concerns with this study. It was noted that this study had five primary outcome measures and was of a tripartite design using primary and secondary care databases and data linkage. The Committee also noted that the Glasgow based part of the study comprised three elements: a quantitative survey; 30 in-depth interviews and a cost benefit analysis. The anonymity issues had been well addressed. The Committee noted the supplementary list of key collaborators. The Committee commented that it was very useful to have been provided with referee's comments and the researchers' responses to these.		
The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation.		
The Committee made the following observations and any changes to the information sheet could be provided to the Secretariat for information:		
Chairman Professor Kennedy Lees Vice-Chairman Dr George Masterton		



1. It would be helpful Avoid inconsistencies contained in the documentation e.g. either refer to colorectal cancer or bowel cancer throughout etc.
2. Whenever possible potential participants should have more time than 24 hours to consider participating in the study before consent was obtained.
3. Avoid the impression in the participant information sheet that phone calls would not cost anything when there would be a cost involved to a potential participant when making the initial contact.
4. The network extends to wider fields than just 'social'.
5. The participant information sheet should:
  1. mention that the study has been reviewed by MREC for Scotland, Committee A.

#### **Ethical review of research sites**

The Committee has designated this study as exempt from site-specific assessment (SSA). The favourable opinion for the study applies to all sites involved in the research. There is no requirement for other Research Ethics Committees to be informed or SSA 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 documents reviewed and approved at the meeting were:

<b>Document</b>	<b>Version</b>	<b>Date</b>
Application		03 January 2006
Investigator CV		29 November 2005
Protocol	2	29 November 2005
Covering Letter		30 November 2005
Letter listing study collaborators		06 January 2006
Topic Guides for In Depth Interview 1	1	10 November 2005
Topic Guides for Second In Depth Interview (12 Months Later)	1	10 November 2005
PICT Questionnaire	1	17 November 2005
Letter of invitation to GP practices - Glasgow Caledonian University	2	22 November 2005



Letter of invitation to GP practices - University of Glasgow	2	22 November 2005
Letter of invitation to GP practices - University of Aberdeen	2	22 November 2005
Participant Information Sheet - Glasgow Caledonian University	1	21 November 2005
Participant Information Sheet - University of Glasgow	2	10 November 2005
Participant Information Sheet - University of Aberdeen	2	10 November 2005
Participant Consent Form - University of Aberdeen	2	10 November 2005
Participant Consent Form - University of Glasgow	2	10 November 2005
Participant Consent Form - Glasgow Caledonian University	2	22 November 2005
Appendix III – Map of Program	1	29 November 2005
Referees' report		22 February 2005
Response to referees' reports		02 March 2005
Grant award letter		02 August 2005

#### **Research governance approval**

You should arrange for all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research at a NHS site must obtain research governance approval from the relevant care organisation before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

#### **Membership of the Committee**

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

#### **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.





*REC reference number: 06/MRE00/3-Please quote this number on all correspondence*

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

Yours sincerely

*Dalw dhu*

*pr* **Professor Kennedy Lees**  
**Chairman**  
*cc: Dr Liz Rattray*  
*Research & Innovation*  
*University of Aberdeen*  
*University Office, King's College*  
*Aberdeen*  
*AB24 3FX*

## 8.2 Letter of R&D approval

Primary Care Division

Research & Development Directorate

Gartnavel Royal Hospital  
1055 Great Western Road  
Glasgow G12 0XH  
Tel: 0141 211 3600  
[www.nhsgg.org.uk](http://www.nhsgg.org.uk)



Dr NC Campbell  
Senior Lecturer  
Department of General Practice  
& Primary Care  
University of Aberdeen  
Foresterhill Health Centre  
Westburn Road  
Aberdeen

Date 28 March 2006  
Your Ref  
Our Ref BR/AW/approve  
Direct Line 0141 211 3661  
Fax 0141 211 3814  
Email [annette.watt@gartnavel.gla.comen.scot.nhs.uk](mailto:annette.watt@gartnavel.gla.comen.scot.nhs.uk)

Dear Dr Campbell

**Project Reference Number: 06CH09**  
**Project Title: Establishing the potential for Primary Care to tackle social inequalities in established colorectal cancer**

Thank you for completing the Research & Development (R&D) Management Approval Application for the above study. I am pleased to inform you that R&D management approval has been granted by Greater Glasgow Primary Care Division subject to the following requirements:

- You should notify me of any changes to the original submission and send regular, brief, interim reports including recruitment numbers where applicable.
- Your research must be conducted in accordance with the National Research Governance standards. (see CSO website: [www.show.scot.nhs.uk/cso](http://www.show.scot.nhs.uk/cso)) Local Research Governance monitoring requirements are presently being developed. This may involve audit of your research at some time in the future.
- You must comply with any regulations regarding data handling (Data Protection Act).
- Brief details of your study will be entered on the National Research Register (NRR). You will be notified prior to the next submission date and asked to check the details being submitted.
- A final report, with an abstract which can be disseminated widely within the NHS, should be submitted when the project has been completed.

Do not hesitate to contact the R & D office if you need any assistance.

Thank you again for your co-operation.

Yours sincerely

*BR*  
**Brian Rae**  
**Research Manager**

CC DE UM MACLEOD



## 8.3 Patient information sheet



### PATIENT INFORMATION SHEET

#### **Study title: Establishing the potential for primary care to tackle social inequalities in patients with bowel cancer**

We would like to invite you to help us with a research study looking at how problems or illnesses that people may have affect their experience of cancer and the care that they receive.

#### ***Why is the study being done?***

How well people with bowel cancer do depends on a number of things including other illnesses and problems that they may have. Your help is important to us because we would like to ensure that patients from all types of backgrounds with colorectal cancer receive the best possible care and treatment. In order to understand what happens in greater detail, we are asking patients in Glasgow and Grampian to assist us. We hope to recruit 200 patients from Glasgow and 360 patients from Grampian.

#### ***Why have you chosen me?***

You have been approached because you have recently been diagnosed with cancer of the bowel and are being cared for by doctors and nurses who are helping with this study.

#### ***Do I have to take part?***

No, taking part is voluntary. If you would prefer not to take part you do not have to give a reason. Your doctor would not be upset and your treatment would not be affected in any way whatsoever. If you do agree to take part you are free to change your mind at any time.

#### ***What will I have to do if I take part?***

The main part of this study involves filling in a questionnaire. This will be done by our researcher, Susan Browne, who will ask you questions about yourself, your background, your health, your social circumstances and the treatment and care that you have received. She will fill in a questionnaire with your responses. This is likely to take about half an hour and can take place when you come to the hospital clinic, or can be done in your own home, if you would prefer.

We will also be asking some people who participate in the study if they would like take part in a more in-depth interview in a few weeks time. The purpose of these

interviews is to help us understand more fully some of the issues covered in the questionnaire. The interviews give us an opportunity to ask people in detail about their illness, health problems and how these are impacting on their life and family. If you agree to take part in the study, Susan will discuss with you whether or not we would also like you to take part in this longer interview. If so, she will arrange to come back and see you at some other time. The interview will last around an hour and will be tape recorded. Susan will then ask for your permission to contact you again after a year, when you are further on from your treatment, to speak to you about whether your views have changed.

We will also ask for your permission to look at your medical notes, from the hospital(s) you have been attending and also your GP's records. This will enable us to find out details about your cancer without having to come and ask you each time. In addition to reviewing your records now, we would like to be able to go back to your records again in the next 5 years to look at the care and treatment that you received.

***What do I do now?***

All you need to do is tell the person who gave you this information sheet (most likely the nurse or doctor at the clinic) that you would like to take part or would like more information about the study. He/she will contact our researcher, Susan Browne, who will then come and see you. She can answer any questions you may have and you can then let her know if you are interested in taking part.

***What will happen to the information collected about me?***

Everything you tell us will be **strictly confidential**. You can refuse to answer any question(s) in the questionnaire or interview without giving a reason. Any information held on computer will be password protected and written files and audiotapes will be stored securely in locked filing cabinets in the Department of General Practice at the University of Glasgow. The information will only be available to the research team and it will be not be identifiable by anything other than a number. The files will be destroyed ten years after the study is complete. We intend to write up our work in reports and papers for medical journals. We would like to assure you that your experiences and opinions will **not** be traceable back to you in any of our publications, and your information will be combined with that of other patients' so that you will not be identified in any way. In addition, your doctors and nurses will not know what you have said to us.

***Who is funding this research?***

This project is being funded by Cancer Research UK

***Who are the research team?***

The project is based at the Universities of Aberdeen, Glasgow and Glasgow Caledonian. The day-to-day researchers for this part of the project are:

*Susan Browne*, who is a Research Fellow at the Department of General Practice, Glasgow and,  
*Una Macleod* who is a GP in Glasgow and Senior Lecturer at the University of Glasgow

You will be able to find out more about the study from our study website at [www.xxxxxxxx](http://www.xxxxxxxx), or by contacting the address below.

Thank you very much for considering taking part in our research. Please discuss this information with your friends, family or doctor if you wish.

Further information can be obtained from:

Susan Browne  
Research Fellow  
Department of General Practice  
& Primary Care  
University of Glasgow  
1 Horselethill Road  
Glasgow G12 9LX  
Tel: 0141 330 8324

Dr Una Macleod  
GP and Senior Lecturer  
Department of General Practice  
& Primary Care  
University of Glasgow  
1 Horselethill Road  
Glasgow G12 9LX  
Tel: 0141 330 8330

# 8.4 Participant consent form



Centre Number:  
 Patient Identification Number:

## CONSENT FORM

**Title of Project:** Establishing the potential for primary care to tackle social inequalities in patients with bowel cancer

Name of Researcher: Susan Browne

**Please initial box**

- 1. I confirm that I have read and understand the information sheet dated 10/11/05 (version No. 2) for the above study and have had the opportunity to ask questions.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
- 3. I understand that my medical notes will be reviewed and information from them used by the research staff involved in this study. I give permission for these individuals to have access to my records.
- 4. I also understand that my General Practitioner will be informed that I have taken part in this study. I give consent for the researcher to review my GP records
- 5. I understand that the research team may wish to review my hospital and GP records again up to five years after initially reviewing them. I give permission for them to do this.
- 6. I understand that I may be asked to take part in an tape recorded in-depth interview.
- 7. I agree to take part in the above study.

Name of Patient	Date	Signature
Researcher	Date	Signature

1 copy for patient; 1 copy for researcher; 1 copy to be kept with hospital notes

Version 2, 10 Nov 2005

## 8.5 Topic guide for first interview



**Study title: Establishing the potential for primary care to tackle social inequalities in patients with bowel cancer**

### TOPIC GUIDE FOR IN DEPTH INTERVIEW 1

The interview will be directed to some extent by the patient, but it is anticipated that the following topics will be covered.

#### **Understanding of diagnosis and treatment**

Can you tell me about your experience since you were diagnosed with bowel cancer?

Can you tell me about any contact you've had with your GP practice since your diagnosis?

Can you tell me about any contact you've had with other health professionals since your diagnosis?

Have these contacts helped you in your recovery?

How could the doctors and nurses looking after you best help you to help yourself?

Are there things that happened that you wish had happened differently?

#### **We are also interested in hearing about other health problems you may have had**

Tell me about any health problems you have or had apart from bowel cancer?

How has the diagnosis and treatment of your bowel cancer affected these other illnesses?

How have these illnesses affected your bowel cancer?

#### **Employment history**

How has your illness affected your work? How do you see the future regarding work?

Has your illness had any financial implications?

#### **Social networks**

How has your illness impacted your daily life?

(including getting out & about, going on holiday, friendships, clubs etc)

Who can you talk to about how you feel / what has been happening to you?

Have you been able to get the practical help you've needed?

Any input from social services (e. g. benefits/grants/rebates/home helps/meals on wheels)?

Has there been any input from voluntary organisations (e. g. BACUP)?

#### **Impact of bowel cancer on life and social networks**

What has the impact of your illness been on you, your family and friends?

Do you feel differently since your diagnosis? Describe how you feel now?

Do you feel able to look after yourself?

What are your expectations of your illness, treatment and care over the next year or so?

## 8.6 Topic guide for second interview

### TOPIC GUIDE FOR SECOND IN DEPTH INTERVIEW (12 MONTHS LATER)

#### Review of events since last interview

Tell me about how you have been since we spoke last time?

What contact have you had with the hospital and with your GP practice in the last year?

Have these contacts helped you in your recovery?

How have you been feeling within yourself?

How differently do you feel now compared with prior to your diagnosis of bowel cancer?

How do you feel about your diagnosis now?

How do you feel about the care and treatment you have received?

#### Other health problems -

– now

– previously

How has the diagnosis and treatment of your bowel cancer affected these other illnesses and vice versa?

#### Medication

– now

– previously

#### Employment history

When did you last work?

What has been the impact of your illness on your work?

#### Social networks

How have your family and friends been in good health over the past year?

Have you been able to talk about how you feel / what has been happening to you?

Any input from social services (e. g. benefits/grants/rebates/home helps/meals on wheels)?

Has there been any input from voluntary organisations (e. g. BACUP)?

#### Impact of bowel cancer on life and social networks

What has the impact of your illness been on you, your family and friends?

Do you feel differently since your diagnosis? Describe how you feel now?

Do you feel able to look after yourself?

How could the doctors and nurses looking after you best help you to help yourself?

What are your expectations of your illness, treatment and care over the next year or so?



## 8.7 Publication from thesis

### Research

Susan Browne, Al Dowie, Liz Mitchell, Sally Wyke, Sue Ziebland, Neil Campbell and Una Macleod

## Patients' needs following colorectal cancer diagnosis:

where does primary care fit in?

#### Abstract

##### Background

Colorectal cancer is the third most common cancer in the UK. Patients with colorectal cancer spend most of their time in the community, but the role of primary care in their management and follow-up is unclear.

##### Aim

To explore colorectal cancer patients' experiences of psychosocial problems and their management in primary and specialist care.

##### Design and setting

Longitudinal qualitative study of participants recruited from three hospitals in the west of Scotland and interviewed in their own homes.

##### Method

In-depth interviews with 24 participants with a new diagnosis of colorectal cancer, and then follow-up interviews 12 months later.

##### Results

Participants' needs following a diagnosis for colorectal cancer included physical, psychological, and social issues. GPs played a key role in diagnosis, after which they were less involved. Participants valued GPs making unsolicited contact and offering support. Participants described being well supported by clinical nurse specialists who are expert in the illness, and who provide continuity of care and psychological support. A year after diagnosis, when there was less contact with GPs and clinical nurse specialists, participants still faced challenges associated with the ongoing impact of colorectal cancer.

##### Conclusion

While some patients enjoyed straightforward recoveries from surgery, others experienced longer-term implications from their disease and treatment, particularly bowel-function issues, fatigue, anxiety, and sexual problems. The potential for primary care to contribute more to the ongoing care of colorectal cancer patients was identified.

##### Keywords

colorectal neoplasms; follow-up studies; primary health care; qualitative research.

#### INTRODUCTION

Colorectal cancer is the third most common cancer in the UK, with 38 600 new cases diagnosed each year. Five-year survival rates have doubled over the past 40 years; around half of those diagnosed will survive for more than 5 years, and those diagnosed at the earliest stage have an over 90% chance of surviving for more than 5 years.<sup>1</sup>

Diagnosis and treatment (usually surgery with or without adjuvant treatment<sup>2</sup>) bring a range of well-documented problems with ongoing impact on a person's physical, psychological, and social wellbeing.<sup>3-4</sup> Some problems relate specifically to colorectal cancer and its treatment (for example, bowel dysfunction); others are problems commonly seen following a cancer diagnosis (for example, psychological distress, fatigue).<sup>7,8</sup>

Patients with colorectal cancer spend little time in hospital, and in countries such as the UK, they are primarily under the care of their GP and primary care team. In recent years, specialist care has included input from clinical nurse specialists, whose role includes the coordination of care between healthcare settings, as well as the provision of advice, information, and psychosocial support for patients and their families.<sup>9,10</sup> Current national guidelines related to

colorectal cancer recommend that all newly diagnosed patients should have access to a clinical nurse specialist from the point of diagnosis.<sup>2,11</sup>

The role of GPs in the care of patients after a diagnosis of cancer is under scrutiny, partly as a result of the cancer care indicator within the general medical services contract Quality and Outcomes Framework,<sup>12</sup> and partly as a result of the survivorship agenda, which is relatively new to the UK,<sup>13</sup> but established in North America in particular.<sup>14</sup> Survivorship strategies are likely to include a shift in emphasis from specialist-based supervised follow-up to personalised care planning, self-management, and tailored support.<sup>15</sup> Despite assertions that point to a central role, with specific expertise in facilitating access to high-quality specialist cancer care, management of comorbidities, and psychosocial care,<sup>16-18</sup> the role of GPs in the care of patients after a diagnosis of cancer is not well researched.

It is timely to consider how patients perceive the role of the primary care team following a diagnosis of colorectal cancer. This paper reports the qualitative findings from a larger study that focused on quality-of-life issues for colorectal cancer patients.<sup>19</sup> The qualitative arm reported here

**S Browne**, MA (Hons), MPhil, research fellow; **Al Dowie**, PhD, Medical and Dental Defence Union of Scotland (MDDUS) senior university teacher, General Practice and Primary Care; **S Wyke**, BSc, PhD, FRCGP (Hon), interdisciplinary research professor, College of Social Sciences, University of Glasgow, Glasgow, Scotland. **ED Mitchell**, BA, PhD, senior research fellow, Social Dimensions of Health Institute, Universities of Dundee and Saint Andrews, Dundee, Scotland. **S Ziebland**, BA (Hons), MSc, research director, DIPEx; university reader in qualitative health research, Department of Primary Health Care, University of Oxford, Oxford. **N Campbell**, MD, PhD, FRCP, FRCGP, reader in general practice, Centre of Academic Primary Care, University of Aberdeen, Scotland. **U Macleod**, professor of

primary care medicine, Hull York Medical School, University of Hull, Hull. **Address for correspondence**

Susan Browne, General Practice and Primary Care, Centre for Population and Health Sciences, College of Medical, Veterinary and Life Sciences, University of Glasgow, 1 Horseleith Road, Glasgow, Scotland, G12 9LX.

**E-mail:** susan.browne@glasgow.ac.uk

**Submitted:** 2 February 2011; **Editor's response:** 10 Mar 2011; **final acceptance:** 31 May 2011.

©British Journal of General Practice

This is the full-length article (published online 31 Oct 2011) of an abridged version published in print. Cite this article as: **Br J Gen Pract 2011; DOI: 10.3399/bjgp11X06582.**

### How this fits in

Colorectal cancer results in patients experiencing physical, psychological, and social challenges. Traditionally, ongoing care has been provided by specialists. This study has identified the potential for a greater role for GPs, in particular, managing digestive dysfunction, fatigue, anxiety, and sexual problems. Unsolicited contact from primary care is appreciated by patients.

sought to explore patient experience of colorectal cancer in more depth, and in particular their management by primary and specialist care.

### METHOD

Participants for the larger study were recruited from hospitals across Scotland. Participants were eligible for inclusion if they had had a definitive diagnosis of colorectal cancer, and had commenced their initial treatment (normally surgery or, in non-resectable cases, palliative radiotherapy or chemotherapy). Participants were excluded if they were unable to give informed consent or, in the opinion of their clinical team, had a life expectancy of less than 1 month. A full description of the recruitment method and sampling strategy used has been given elsewhere.<sup>19</sup> Participants for the qualitative arm were recruited by one researcher via three hospitals in central Scotland. Potential participants had indicated their willingness to take part in the qualitative phase as part of a questionnaire completed in the larger study. They were then approached by telephone, when the aim of the interview study was explained, and a suitable time for interview was arranged if they were still willing to take part. Written consent for this was obtained when they met with the researcher. The study sought to capture a wide range of experiences and, as such, a maximum variation sample was sought.<sup>20</sup> The sampling frame was informed by sociodemographic and clinical characteristics (for example, age, sex, socioeconomic status, level of coexisting morbidity), and participants were selected purposively to ensure adequate representation of patients across these attributes. Typically, qualitative studies do not include large numbers of participants,<sup>21</sup> and the sample size was based on achieving a sufficient number to capture differences in patient experience. Interviews were completed when interviews revealed no new

ideas, experiences, or insights.

First-wave interviews were conducted by one researcher during 2006/2007 and follow-up interviews 12 months later by the same researcher. Initial interviews lasted about an hour, while follow-up interviews were generally shorter. Interviews were carried out in the participants' homes. All interviews were audiotaped and transcribed verbatim.

Twenty-four colorectal cancer patients undertook an in-depth interview within 3 months of diagnosis with colorectal cancer; 19 of these patients were reinterviewed 12 months later. Interview guides were developed prior to interview and included questions on the role of GPs, other primary care professionals, hospital specialists, and clinical nurse specialists; self-care; social networks; and input from families.

Two researchers independently read and re-read the transcripts, after which a coding frame was jointly developed. The raw data were coded thematically, following discussion on emerging themes between the two researchers and with the wider study team. Some key themes like 'patient experience of care' and 'patient need' were identified prior to analysis, based on the aims of the study.<sup>22</sup> Additional themes, such as 'the role of the clinical nurse specialist', were identified from the data, following systematic and interpretative analysis. Transcripts were further read and coded to identify patterns, similarities, and differences in the data. Deviant (or contradictory) cases were actively sought in order to refine the analysis and ensure validity. QSR NVivo 2.0 was used to facilitate data retrieval and coding, analysis of themes, and systematic comparison (<http://www.qsrinternational.com>).

### RESULTS

The sample comprised nine males and 15 females aged from 34 to 84 years, and included a range of Dukes stages (Table 1). Twenty-two participants had had surgery, one was receiving palliative treatment, and one was receiving chemoradiation while they attempted to lose weight to become fit for surgery.

It was not possible to re-interview five participants, as two had died, one felt too unwell to be interviewed, and two were no longer contactable.

### Patient-identified problems

The problems discussed by the responders included physical, psychological, and social issues.

**Table 1. Participant characteristics**

Characteristics	Patients (n = 24)
<b>Number of interviews</b>	
1	5
2	19
<b>Age at first interview, years</b>	
≤50	5
50–70	12
≥70	7
<b>Employment status</b>	
Employed/self-employed	7
Retired	14
Unemployed	2
Looks after home	1
<b>Dukes stage</b>	
A	4
B	9
C	7
D	2
Missing	2
<b>Sex</b>	
Female	15
Male	9
<b>Education level</b>	
No formal qualifications	10
O levels/A levels	5
University/college degree	2
Other qualifications	7
<b>Deprivation quintile</b>	
1 (most affluent)	7
2	4
3	1
4	3
5 (most deprived)	9
<b>Stoma</b>	
None	19
Temporary	2
Permanent	3

**Physical issues.** Participants who had undergone surgery said they experienced ongoing digestive dysfunction problems, including reduced bowel control, faecal urgency, increased frequency of bowel movements, diarrhoea, constipation, and increased flatulence:

*'I got it [surgery] done in June or something and it took right up tae December, January the start of January and up tae then I had more or less constant diarrhoea.'* [male, age 81 years, interview 2 of 2]

Sexual issues were a problem for some, for example, the participant below, had been unable to achieve an erection since surgery:

*'Also trying tae resume a sexual relation with my wife again which I found great*

*difficulty [with] ... I think we were getting to the age where, you know, it starts tae tail off a bit anyway your sex life eh it would be nice tae have it noo and again right enough tae have the option ... But definitely the operation has done something.'* [male, age 55 years, interview 1 of 2]

Additional physical problems following surgery included physical fatigue, weakness, sleep difficulties, pain associated with adhesions, infected wounds, and wounds that were not healing.

A year later, most participants said their physical health had improved but physical issues persisted. Tiredness was the main ongoing issue, even into the second year after diagnosis:

*'I just never been right since I had the operation. I havenae got any energy at all.'* [female, age 64, interview 2 of 2]

*'I was still tired and to tell you the truth I'm still tired, sometimes I'm very tired, I don't know what that's to do with but at the weekend there I just felt absolutely exhausted really. So I don't know whether that's normal or not, normal or what, I don't know. I'm abnormally, well at the weekend I felt I was abnormally tired, you know, I could hardly bring myself to do anything and it just sort of reminded me of the way I was when I came home from hospital, you know.'* [female, age 67 years, interview 2 of 2]

Digestive dysfunction issues also persisted and there was discussion around diets, which had been altered to avoid constipation, diarrhoea, wind, and abdominal pain. Sexual issues still posed problems. One woman said intercourse had become painful, something she had not discussed with any health professional.

**Psychological issues.** Uncertainty emerged as a key theme: uncertainty about what lay ahead, often in terms of the effect and effectiveness of treatment. Uncertainty was described about surgery, [surviving surgery, the effectiveness of surgery, complications with surgery, whether a stoma would be required], whether the cancer might have spread, the cancer being treatable, death, and the impact of their illness on their families. Additional psychological challenges included participants' struggle to understand what had caused their cancer, problems with self-image associated with scars, weight loss, or stomas, and coping with chemotherapy, especially the dread of feeling unwell. These issues were

understood to have led to feelings of anxiety.

One year later, the focus of participants' anxieties had shifted to the possibility of cancer returning:

*'Every so often obviously it comes into your head and you do scenarios and panic.'* (male, age 59 years, interview 2 of 2)

These fears could be triggered by pain and the worry that it might be associated with a recurrence. Fears were heightened whenever participants attended investigations at follow-up appointments:

*'If you've got a pain or something like that you think "oh what's that?" and then you think "oh I hope it's not anything to do with what I've had".'* (female, age 34 years, interview 2 of 2)

*'When I was there getting that scan I was still scared. You heard some stories [in hospital] and you think you're alright but they would say "Oh I had that" and the next time they've went back and they've thought they were all clear and it's not been all clear.'* (female, age 65 years, interview 2 of 2)

**Social issues.** The physical and psychological effects of colorectal cancer impacted the social dimensions of participants' lives, particularly work and relationships. Returning to work posed problems as participants endeavoured to deal with physical issues such as digestive dysfunction and fatigue away from home:

*'I went back to work 4 weeks after my chemo finished ... But I only went back like for two mornings I only did about 9 till 12 it was just in the office really it was just sitting doing paperwork and then the Christmas holidays. Then after the Christmas holidays ... I did like one full day one week and then the next week I did two full days, the next week three full days ... I've been back full time since then.'* (female, age 37 years, interview 2 of 2)

Travel and holidays featured in the second interviews, with discussion of managing digestive dysfunction issues while travelling, and managing diet away from home.

Support from spouses, both practical and emotional, was cited as the key source of support for the majority of participants soon after diagnosis, and again a year later. Participants' partners provided practical support with domestic chores, cooking, and driving, but providing this support could prove difficult, particularly where partners

were older or not physically fit themselves.

#### **Professional input accessed by participants to address needs**

##### *Support from clinical nurse specialists.*

Support from clinical nurse specialists was highly valued because they had expert knowledge of colorectal cancer, they provided continuity of care, they were accessible, and their expertise extended from the illness itself to treatment, treatment effects, and side effects, and to the wider psychological and social implications of the disease:

*'I was concerned going to the toilet many times, many times, you know and she said that she was not surprised because usually because they cut near the rectum that's why she said she was not surprised I was going to the toilet many times.'* (female, age 50 years, interview 1 of 2)

The continued presence of clinical nurse specialists from diagnosis through to subsequent consultations, follow-up clinics, and telephone contact ensured continuity of care. In addition, the nurses provided access to the surgeon's knowledge — taking queries to the surgeon and informing participants of the surgeon's advice. Some of the uncertainty participants felt was addressed with explanations of treatment plans and what they might expect to happen:

*'Oh yeah, uh huh, because what she did was ... she put it into sequence of events and when things would happen and I took a note there and then and that was a big help.'* (female, age 68 years, interview 1 of 2)

Sometimes clinical nurse specialists showed people the high-dependency unit and introduced them to other health professionals who would be involved in their care. One man said the one person he felt able to talk about his illness with was the clinical nurse specialist. Another woman discussed fears about death with the clinical nurse specialist. Participants said clinical nurse specialists had urged them to get in touch if they had problems coping:

*'Well certainly X [the nurse] has just been a great help about discussing em the current situation and also how things may develop and just really, you know, you need to, because you're not sure, you haven't been through this before you're not sure what may happen next. And just, you know, putting me at ease.'* (male, age 51 years, interview 1 of 1)

*Also just checking anything to do with like the, you know, the wigs or anything or feeling emotionally upset or if there's any other problems, family problems anything like that she's just there.'* [female, age 55 years, interview 1 of 1]

**Primary care support.** For the majority of participants, GPs played a key role in the diagnostic process, typically referring to secondary care. GPs featured much less in participants' accounts of care accessed after diagnosis:

*The last time I saw my doctor was when he got me my appointment for X [the hospital] and that was months before I had my operation.'* [male, age 75 years, interview 1 of 1]

Some participants were contacted by their GPs on their return home from hospital after surgery. GPs either telephoned or called in person, and offered their support and enquired about participants' recovery:

*She just wanted to know how things were, she phoned and said "Make an appointment". Just to see how I was and how I was coping and then once the chemo started I got in touch with her again 'cause she wants to know how I'm coping with the treatment. And if I had any queries at all I could phone her 'cause she's easy to talk to.'* [female, age 72 years, interview 1 of 1]

This contact was unsolicited and was appreciated by participants, who were comforted by the knowledge that help was available [and occasionally the lack of an unsolicited contact was a source of dissatisfaction]:

*I was a bit disappointed in her after my operation because eh so many folk said "Your doctor will make a courtesy call" and she didn't bother.'* [female, age 70 years, interview 2 of 2]

GPs flagged up the possibility of psychological issues arising with a cancer diagnosis, and offered to help should the need arise. However, accounts of consulting GPs on the psychological impact of colorectal cancer were rare: very few participants mentioned, or planned to mention to their GPs the anxiety they felt.

Where participants contacted their GPs, consultations were primarily regarding physical matters including digestive dysfunction problems, problems with

wounds, and side effects from chemotherapy. In a few instances, GPs assisted participants with social challenges associated with colorectal cancer, for example, helping with a cancer charity grant application. Contact with district nurses tended to be for short-term wound management, and 1 year later no one was still seeing a district nurse.

One year later, contact with GPs was seldom with regard to issues associated with colorectal cancer. Those who were seeing their GP regarding other issues occasionally mentioned issues related to colorectal cancer as an aside. A minority did consult their GP on the ongoing impact of their colorectal cancer, particularly the physical aspects such as fatigue and diarrhoea.

Health professionals were not consulted by all the participants who experienced problems associated with their colorectal cancer, but those who did seek advice regarding issues related to colorectal cancer often chose to consult secondary care, most usually their clinical nurse specialist.

**Barriers to accessing primary care.** When asked why they had not contacted primary care about ongoing issues associated with colorectal cancer, responders typically replied that they 'didn't like bothering people':

*I haven't asked for any help. I'm a bit like that mind you. I wouldn't ask unless I, I don't like bothering people, em, so I would have to be sure I should ask really, really, really sure. Why did I originally go? Why I do not, I don't know. I was so lucky. I was so sensible why it's just not like me I tell you.'* [female, age 64 years, interview 2 of 2]

Some said that if they were going to seek help they would first consult a clinical nurse specialist, suggesting that there may have been greater perceived barriers to accessing care from primary care than from a clinical nurse specialist. Disincentives to contacting primary care cited by participants were the perceived lack of expertise related to colorectal cancer, and the lack of ongoing contact throughout the illness. They also spoke of issues around accessibility compared to phoning a clinical nurse specialist directly, as well as the GP's inability to provide emotional support directly, in comparison to conversations with clinical nurse specialists, where they had previously sought advice and reassurance, and had voiced their fears.

However, it may also be the case that consulting a clinical nurse specialist in the first instance is simply a reflection of the perceived expert role of the nurse, combined with the continuity that nurse specialists offer as a direct point of contact.

Elsewhere, participants chose not to consult their GP on issues associated with their colorectal cancer because their faith in their GP had been eroded during a problematic diagnostic process. Although GPs often pursued other avenues of investigation before referring to secondary care, there were instances where participants felt the time between their initial presentation with symptoms and their referral to secondary care was unnecessarily long, and constituted poor care:

*'I wouldn't phone them [the GP], I've no confidence in them at all even when I was poorly after I came home after 7 days and I wasn't well, I really wasn't well. I thought I'll have to get a doctor out or something, I can't cope with this, I phoned the hospital and they said 'Just bring her in'. So I did that rather than phone my GP because they're more supportive.'* (female, age 53 years, interview 1 of 2)

## DISCUSSION

### Summary

In the months following diagnosis, participants faced physical issues, particularly digestive dysfunction and sexual problems. Later, fatigue emerged as the most prominent physical challenge, with some digestive dysfunction and sexual problems persisting. Uncertainties and anxieties about the future were the greatest psychological challenges described in the first interviews. Later anxieties were focused on the fear of recurrence. Colorectal cancer impacted the social dimensions of participants' lives, resulting in protracted absences from work and difficulties travelling.

Some participants had discussed physical problems with their GPs but few had visited their GPs with regard to psychosocial problems. This was particularly the case 1 year after diagnosis, in spite of the enduring nature of many issues.

Clinical nurse specialists were preferred to primary care for support, for both their accessibility and expertise. Barriers to primary care involvement in care emerged as reluctance to bother their GP and instances in which diagnosis was felt by participants to have taken longer than necessary.

### Strengths and limitations

The main strength of this study is that it reports in-depth interviews with newly diagnosed cancer patients and again 12 months later, exploring their needs at both times and how they were being met. Participants were not chosen on grounds of delay in diagnosis, yet this emerged as an issue.

Specialist nurses recruited patients to the larger study that incorporated this qualitative arm, and it is possible that there was selection bias towards those that they were more involved with, perhaps explaining the patients' lack of contact with primary care. In addition, patients perceived by nurses to be too ill to be included may not have been approached, and it is possible that this group may have had more contact with primary care following discharge from hospital. However, the participants in this qualitative study were recruited directly by the researcher, and were purposively selected to ensure maximum variation in responder characteristics. Sampling was informed by both patient and clinical factors, including stage of cancer, and coexisting chronic illness, and it is likely that recruiting patients to represent the spectrum of these characteristics (early and late-stage cancers, comorbidity and no comorbidity, affluent and deprived) will have mitigated any potential bias. In addition, lack of primary care contact persisted into the second interview a year later, at a time when the specialist nurses had far less involvement with patients, suggesting that this is a real observation that is unrelated to clinical nurse specialist input.

### Comparison with existing literature

Previous work has identified similar needs following a diagnosis of colorectal cancer.<sup>3,23,24</sup> Although others have identified the potential importance of the role of primary care in addressing physical, psychological, and social issues following a cancer diagnosis,<sup>16,17</sup> this study showed these needs to be unmet, and that patients often did not identify their GP as the main source of potential help in meeting such needs. Patients identified with their nurse specialist, with whom they had built a relationship. However, they did place importance on contact from their GP, initiated by the GP soon after diagnosis.

### Implications for practice

This study provides a basis for considering the appropriate role for primary care with respect to the survivorship agenda. It is increasingly likely that patients will have

### Funding

This study was funded by Cancer Research UK (reference no: C542/A6502).

### Ethical approval

Ethics approval was given by MREC for Scotland, Committee A.

### Provenance

Freely submitted; externally peer reviewed.

### Competing interests

The authors have declared no competing interests.

### Acknowledgements

We thank the patients who took part in this study, the clinical nurse specialists for their help with recruitment, and Catherine McNeil for secretarial support.

### Discuss this article

Contribute and read comments about this article on the Discussion Forum: <http://www.rcgp.org.uk/bjgp-discuss>

---

limited contact with specialists, and that this will be dependent on their treatments; so, for example, patients receiving adjuvant or palliative chemotherapy will have more prolonged contact. Those who do not require such treatments will be discharged from specialist care earlier. It is therefore important that patients have information, not just about their cancer and its treatments, but also about likely symptoms (both cancer-specific and general) and know where to seek help for these. Many of these symptoms are ones that primary care has great experience in dealing with, but according to the results of this study, GPs are not necessarily being contacted by patients. For colorectal cancer patients, these include symptoms such as diarrhoea and constipation, and sexual problems, and for cancer patients more generally, symptoms such as fatigue, anxiety, low mood, and other psychosocial problems.

Other specific issues for clinical practice arose from this study. First, where

participants feel their diagnosis has taken longer than ideal, this should be directly addressed. There were other participants who had delayed diagnosis yet continued to have faith in their GPs as they understood why alternative explanations for symptoms had been investigated first. Secondly, GPs should contact patients after a cancer diagnosis and offer practice and personal input. This would provide an opportunity for discussing and addressing patients' needs and providing information about ongoing needs and support. Contact of this kind would include the opportunity to engage with patients about the uncertainties of their diagnosis and treatment options, seeking to allay uncertainty where appropriate. If this happened as a matter of routine, it can be postulated that primary care would be seen as a core part of the ongoing care of patients with cancer, not just by those with a specific interest in the topic,<sup>14</sup> but by patients themselves, who at present too often view the role of primary care as peripheral.

## REFERENCES

1. Cancer Research UK. *Bowel cancer statistics – UK*. <http://info.cancerresearchuk.org/cancerstats/types/bowel/> [accessed 11 Jul 2011].
2. Scottish Intercollegiate Guideline Network. *Management of colorectal cancer: guidelines (SIGN 67)*. Edinburgh: SIGN, 2003. <http://www.sign.ac.uk/guidelines/fulltext/67/index.html> [accessed 11 Jul 2011].
3. Sahay TB, Gray RE, Fitch M. A qualitative study of patient perspectives on colorectal cancer. *Cancer Pract* 2000; **8(1)**: 38–44.
4. Denlinger CS, Barsevick AM. The challenges of colorectal cancer survivorship. *J Natl Compr Canc Netw* 2009; **7(8)**: 883–893.
5. Phipps E, Braitman LE, Stiles S, et al. Quality of life and symptom attribution in long-term colon cancer survivors. *J Eval Clin Pract* 2008; **14(2)**: 254–252.
6. Rozmovits L, Ziebland S. Expressions of loss of adulthood in the narratives of people with colorectal cancer. *Qual Health Res* 2004; **14(2)**: 187–203.
7. Carlson LE, Angen M, Cullum J, et al. High levels of untreated distress and fatigue in cancer patients. *Br J Cancer* 2004; **90(12)**: 2297–2304.
8. Sharpe M, Strong V, Allen K, et al. Major depression in outpatients attending a regional cancer centre: screening and unmet treatment needs. *Br J Cancer* 2004; **90(2)**: 314–320.
9. National Cancer Action Team, Macmillan Cancer Support. *Quality in nursing. Excellence in cancer care: the contribution of the clinical nurse specialist*. London: Department of Health, 2010. <http://www.macmillan.org.uk/Documents/AboutUs/Commissioners/ExcellenceinCancerCaretheContributionoftheClinicalNurseSpecialist.pdf> [accessed 11 Jul 2011].
10. Daly WM, Carnwell R. Nursing roles and levels of practice: a framework for differentiating between elementary, specialist and advancing nursing practice. *J Clin Nursing* 2003; **12(2)**: 158–167.
11. National Institute for Health and Clinical Excellence (NICE). *Improving outcomes in colorectal cancers: manual update*. London: NICE, 2004. <http://www.nice.org.uk/nicemedia/live/10895/28832/28832.pdf> [accessed 11 Jul 2011].
12. British Medical Association. *Investing in general practice: the new general medical services contract*. London: BMA, 2004.
13. Department of Health. *The National Cancer Survivorship Initiative Vision*. London: Department of Health, 2010.
14. Jacobs LA, Palmer SC, Schwartz LA, et al. Adult cancer survivorship: evolution, research, and planning care. *CA Cancer J Clin* 2009; **59(6)**: 391–410.
15. Nekhlyudov L. 'Doc, should I see you or my oncologist?': a primary care perspective on opportunities and challenges in providing comprehensive care for cancer survivors. *J Clinical Oncol* 2009; **27(15)**: 2424–2426.
16. Campbell NC, Macleod U, Weller D. Primary care oncology: essential if high quality cancer care is to be achieved for all. *Fam Pract* 2002; **19(6)**: 577–578.
17. Pascoe SW, Neal RD, Algar VL, et al. Psychosocial care for cancer patients in primary care? Recognition of opportunities for cancer care. *Fam Pract* 2004; **21(4)**: 437–442.
18. Earle CC, Neville BA. Under use of necessary care among cancer survivors. *Cancer* 2004; **101(8)**: 1712–1719.
19. Gray NM, Hall SJ, Browne S, et al. Modifiable and fixed factors predicting quality of life in people with colorectal cancer. *Br J Cancer* 2011; **104(11)**: 1697–1703.
20. Sandelowski M. Sample size in qualitative research. *Res Nurs Health* 1995; **18(2)**: 179–183.
21. Marshall MN. Sampling for qualitative research. *Fam Pract* 1996; **13(6)**: 522–526.
22. Kelle U. Theory building in qualitative research and computer programs for the management of textual data. *Sociological Res Online* 1997; **2(2)** <http://www.socresonline.org.uk/2/2/1.html> [accessed 11 Jul 2011].
23. Rozmovits L, Rose P, Ziebland S. In the absence of evidence, who chooses? A qualitative study of patients' needs after treatment for colorectal cancer. *J Health Serv Res Policy* 2004; **9(3)**: 159–164.
24. Simpson MF, Whyte F. Patients' experiences of completing treatment for colorectal cancer in a Scottish District General Hospital. *Eur J Cancer Care* 2006; **15(2)**: 172–182.



## References

- Adams, E., Boulton, M., & Watson, E. (2009). The information needs of partners and family members of cancer patients: a systematic literature review. *Patient education and counseling*, 77(2), 179.
- Adams, E., Boulton, M., Rose, P. W., Lund, S., Richardson, A., Wilson, S., & Watson, E. K. (2012). A qualitative study exploring the experience of the partners of cancer survivors and their views on the role of primary care. *Supportive Care in Cancer*, 20(11), 2785-2794.
- Adams, E., Boulton, M., Rose, P., Lund, S., Richardson, A., Wilson, S., & Watson, E. (2011). Views of cancer care reviews in primary care: a qualitative study. *The British Journal of General Practice*, 61(585), e173.
- Armes, J., Crowe, M., Colbourne, L., Morgan, H., Murrells, T., Oakley, C., ... & Richardson, A. (2009). Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey. *Journal of Clinical Oncology*, 27(36), 6172-6179.
- Aziz, N. M., & Rowland, J. H. (2003). Trends and advances in cancer survivorship research: challenge and opportunity. In *Seminars in radiation oncology* (Vol. 13, No. 3, p. 248).
- Bain, N. S., Campbell, N. C., Ritchie, L. D., & Cassidy, J. (2002). Striking the right balance in colorectal cancer care—a qualitative study of rural and urban patients. *Family practice*, 19(4), 369-374.
- Barnett, K., Mercer, S. W., Norbury, M., Watt, G., Wyke, S., & Guthrie, B. (2012). Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *The Lancet*.  
Supplementary appendix  
<http://download.thelancet.com/mmcs/journals/lancet/PIIS0140673612602402/mmc1.pdf?id=f1b40765af4fa604:623dc8de:13e3875c729:aad1366749489718>
- Baum, F. (1995). Researching public health: behind the qualitative-quantitative methodological debate. *Social Science & Medicine*, 40(4), 459-468.
- Beech, N., Arber, A., & Faithfull, S. (2012). Restoring a sense of wellness following colorectal cancer: a grounded theory. *Journal of advanced nursing*, 68(5), 1134-1144.
- Bekkers, M. J. T. M., Van Knippenberg, F. C. E., Van Dulmen, A. M., Van Den Borne, H. W., & van Berge Henegouwen, G. P. (1997). Survival and psychosocial adjustment to stoma surgery and nonstoma bowel resection: a 4-year follow-up. *Journal of psychosomatic research*, 42(3), 235-244.

- Berterö, C. (2012). Grounded theory methodology-has it become a movement?. *International Journal of Qualitative Studies on Health and Well-being*, 7.
- Boudioni, M., McPherson, K., Moynihan, C., Melia, J., Boulton, M., Leydon, G., & Mossman, J. (2001). Do men with prostate or colorectal cancer seek different information and support from women with cancer?. *British journal of cancer*, 85(5), 641.
- Bowen, G. A. (2008). Naturalistic inquiry and the saturation concept: a research note. *Qualitative research*, 8(1), 137-152.
- Brashers, D. E., Neidig, J. L., Russell, J. A., Cardillo, L. W., Haas, S. M., Dobbs, L. K., ... & Nemeth, S. (2003). The medical, personal, and social causes of uncertainty in HIV illness. *Issues in Mental Health Nursing*, 24(5), 497-522.
- British Medical Association. (2004). *Investing in General Practice: The New General Medical Services Contract*. London: BMA.
- Broughton, M., Bailey, J., & Linney, J. (2004). How can experiences of patients and carers influence the clinical care of large bowel cancer?. *European journal of cancer care*, 13(4), 318-327.
- Brown, H., & Randle, J. (2005). Living with a stoma: a review of the literature. *Journal of clinical nursing*, 14(1), 74-81.
- Browne, S., Dowie, A., Mitchell, L., Wyke, S., Ziebland, S., Campbell, N., & Macleod, U. (2011). Patients' needs following colorectal cancer diagnosis: where does primary care fit in?. *British Journal of General Practice*, 61(592), 692-699.
- Bryman, A. (2004). *Social research methods*. Oxford: OUP
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of health & illness*, 4(2), 167-182.
- Bury, M. (1991). The sociology of chronic illness: a review of research and prospects. *Sociology of Health & Illness*, 13(4), 451-468.
- Camilleri-Brennan, J., & Steele, R. J. C. (2002). Objective assessment of morbidity and quality of life after surgery for low rectal cancer. *Colorectal disease*, 4(1), 61-66.
- Campbell, N. C., MacLeod, U., & Weller, D. (2002). Primary care oncology: essential if high quality cancer care is to be achieved for all. *Family Practice*, 19(6), 577-578.
- Carlson, L. E., Angen, M., Cullum, J., Goodey, E., Koopmans, J., Lamont, L., ... & Bultz, B. D. (2004). High levels of untreated distress and fatigue in cancer patients. *British Journal of Cancer*, 90(12), 2297-2304.

- Carter, B. J. (1993). Long-term survivors of breast cancer: A qualitative descriptive study. *Cancer Nursing*, 16(5), 354-361.
- Charmaz, K. (1994). Identity dilemmas of chronically ill men. *The Sociological Quarterly*, 35(2), 269-288.
- Charmaz, K. (1995). The body, identity, and self. *The Sociological Quarterly*, 36(4), 657-680.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Sage Publications Limited.
- Cornwell, J. (1984). *Hard-earned lives: Accounts of health and illness from East London*. London: Tavistock.
- Daly, W. M., & Carnwell, R. (2003). Nursing roles and levels of practice: a framework for differentiating between elementary, specialist and advancing nursing practice. *Journal of clinical nursing*, 12(2), 158-167.
- Decosse, J. J., & Cennerazzo, W. J. (1997). Quality-of-life management of patients with colorectal cancer. *CA: A Cancer Journal for Clinicians*, 47(4), 198-206.
- Denlinger, C. S., & Barsevick, A. M. (2009). The challenges of colorectal cancer survivorship. *Journal of the National Comprehensive Cancer Network*, 7(8), 883-894.
- Department of Health, Macmillan Cancer Support, & NHS Improvement. (2010). *National Cancer Survivorship Initiative: Vision*. London: Department of Health
- Department of Health. (2005). *Supporting people with long term conditions*. London: Department of Health
- Department of Health. (2007). *Generic choice model for long term conditions*. London: Department of Health
- Department of Health. (2009). *Cancer Reform Strategy 2nd Annual Report*. London: Department of Health
- Department of Health. (2010). *The National Cancer Survivorship Initiative Vision*. London: Department of Health
- Department of Health. (2011). *Improving outcomes: a strategy for cancer*. London: Department of Health
- Desnoo, L., & Faithfull, S. (2006). A qualitative study of anterior resection syndrome: the experiences of cancer survivors who have undergone resection surgery. *European journal of cancer care*, 15(3), 244-251.

Douglas, M. (1982). *Natural symbols*. New York: Pantheon.

Douglas, M. (1985). *Purity and danger*. London: ARK.

Dudas, K., Olsson, L. E., Wolf, A., Swedberg, K., Taft, C., Schaufelberger, M., & Ekman, I. (2013). Uncertainty in illness among patients with chronic heart failure is less in person-centred care than in usual care. *European Journal of Cardiovascular Nursing*.

Dunn, J., Lynch, B., Rinaldis, M., Pakenham, K., McPherson, L., Owen, N., ... & Aitken, J. (2006). Dimensions of quality of life and psychosocial variables most salient to colorectal cancer patients. *Psycho-Oncology*, 15(1), 20-30.

Earle, C. C., & Neville, B. A. (2004). Under use of necessary care among cancer survivors. *Cancer*, 101(8), 1712-1719.

Elias, N. (2000). *The civilizing process* (E. Jephcott, Trans.) (Rev. ed.). Oxford, UK: Basil Blackwell. (Original work published 1939)

Elliott, J., Fallows, A., Staetsky, L., Smith, P. W. F., Foster, C. L., Maher, E. J., & Corner, J. (2011). The health and well-being of cancer survivors in the UK: findings from a population-based survey. *British journal of cancer*, 105, S11-S20.

Emslie, C., Browne, S., MacLeod, U., Rozmovits, L., Mitchell, E., & Ziebland, S. (2009). 'Getting through' not 'going under': A qualitative study of gender and spousal support after diagnosis with colorectal cancer. *Social science & medicine* (1982), 68(6-9), 1169.

Engel, J., Kerr, J., Schlesinger-Raab, A., Eckel, R., Sauer, H., & Hölzel, D. (2003). Quality of life in rectal cancer patients: a four-year prospective study. *Annals of surgery*, 238(2), 203.

Faircloth, C. A., Boylstein, C., Rittman, M., Young, M. E., & Gubrium, J. (2004). Sudden illness and biographical flow in narratives of stroke recovery. *Sociology of health & illness*, 26(2), 242-261.

Foster, C., & Fenlon, D. (2011). Recovery and self-management support following primary cancer treatment. *British journal of cancer*, 105, S21-S28.

Foster, C., Wright, D., Hill, H., Hopkinson, J., & Roffe, L. (2009). Psychosocial implications of living 5 years or more following a cancer diagnosis: a systematic review of the research evidence. *European journal of cancer care*, 18(3), 223-247.

Galloway, S. C., & Graydon, J. E. (1996). Uncertainty, symptom distress, and information needs after surgery for cancer of the colon. *Cancer nursing*, 19(2), 112-117.

- Ganz, P. A. (2005). A teachable moment for oncologists: cancer survivors, 10 million strong and growing!. *Journal of Clinical Oncology*, 23(24), 5458-5460.
- Gennep, A. V. (1960). *The rites of passage*. Chicago: University of Chicago Press. (Originally published in 1909)
- Gilbar, O., & Ben-Zur, H. (2002). *Cancer and the family caregiver: Distress and coping*. Charles C Thomas Publisher.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Aldine de Gruyter.
- Gray, N. M., Hall, S. J., Browne, S., Macleod, U., Mitchell, E., Lee, A. J., ... & Campbell, N. C. (2011). Modifiable and fixed factors predicting quality of life in people with colorectal cancer. *British journal of cancer*, 104(11), 1697-1703.
- Guba, E.G. & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In: Denzin N. & Lincoln Y. S., (eds.), *Handbook of qualitative research*. (pp. 105-117). California: SAGE.
- Hagedoorn, M., Sanderman, R., Bolks, H. N., Tuinstra, J., & Coyne, J. C. (2008). Distress in couples coping with cancer: a meta-analysis and critical review of role and gender effects. *Psychological bulletin*, 134(1), 1.
- Hall, S., Gray, N., Browne, S., Ziebland, S., & Campbell, N. C. (2012). A qualitative exploration of the role of primary care in supporting colorectal cancer patients. *Supportive Care in Cancer*, 20(12), 3071-3078.
- Hammersley, M. (1992) Deconstructing the qualitative- quantitative divide. In: Hammersley, M. ( ed.), *What's wrong with ethnography?* (pp. 159- 173). London: Routledge,
- Harrison, S. E., Watson, E. K., Ward, A. M., Khan, N. F., Turner, D., Adams, E., ... & Rose, P. W. (2012). Cancer survivors' experiences of discharge from hospital follow-up. *European journal of cancer care*, 21(3), 390-397.
- Hewitt, M., & Rowland, J. H. (2002). Mental health service use among adult cancer survivors: analyses of the National Health Interview Survey. *Journal of Clinical Oncology*, 20(23), 4581-4590.
- Hewitt, M., Greenfield, S., & Stovall, E. (Eds.). (2005). *From cancer patient to cancer survivor: lost in transition*. National Academies Press.
- Hewitt, M., Rowland, J. H., & Yancik, R. (2003). Cancer survivors in the United States: age, health, and disability. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 58(1), M82-M91.

- Houldin, A. D. (2007). A qualitative study of caregivers' experiences with newly diagnosed advanced colorectal cancer. In *Oncology nursing forum* (Vol. 34, No. 2, pp. 323-330). Oncology Nursing Society.
- Houldin, A. D., & Lewis, F. M. (2006). Salvaging their normal lives: a qualitative study of patients with recently diagnosed advanced colorectal cancer. In *Oncology nursing forum* (Vol. 33, No. 4, pp. 719-725). Oncology Nursing Society.
- Hubbard, G., Kidd, L., & Kearney, N. (2010). Disrupted lives and threats to identity: the experiences of people with colorectal cancer within the first year following diagnosis. *Health*, 14(2), 131-146.
- Jacobs, L. A., Palmer, S. C., Schwartz, L. A., DeMichele, A., Mao, J. J., Carver, J., ... & Meadows, A. T. (2009). Adult cancer survivorship: evolution, research, and planning care. *CA: A Cancer Journal for Clinicians*, 59(6), 391-410.
- James, N. (1989). Emotional labour: skill and work in the social regulation of feelings. *The Sociological Review*, 37(1), 15-42.
- Kelle, U. (1997). Theory Building in Qualitative Research and Computer Programs for the Management of Textual Data. *Sociological Research Online*, 2(2) <http://www.socresonline.org.uk/2/2/1.html>
- Kendall, M., Boyd, K., Campbell, C., Cormie, P., Fife, S., Thomas, K., ... & Murray, S. A. (2006). How do people with cancer wish to be cared for in primary care? Serial discussion groups of patients and carers. *Family Practice*, 23(6), 644-650.
- Khan, N. F., Evans, J., & Rose, P. W. (2011). A qualitative study of unmet needs and interactions with primary care among cancer survivors. *British journal of cancer*, 105, S46-S51.
- Khan, N. F., Mant, D., Carpenter, L., Forman, D., & Rose, P. W. (2011). Long-term health outcomes in a British cohort of breast, colorectal and prostate cancer survivors: a database study. *British journal of cancer*, 105, S29-S37.
- Khan, N. F., Ward, A., Watson, E., Austoker, J., & Rose, P. W. (2008). Long-term survivors of adult cancers and uptake of primary health services: a systematic review. *European Journal of Cancer*, 44(2), 195-204.
- Killoran, M., Schlitz, M. J., & Lewis, N. (2002). "Unremarkable" Recoveries: Normalizing Adversity and Cancer Survival. *Qualitative health research*, 12(2), 208-222.
- Klemm, P., Miller, M. A., & Fernsler, J. (2000). Demands of illness in people treated for colorectal cancer. In *Oncology nursing forum* (Vol. 27, No. 4, p. 633).
- Lawton, J. (1998). Contemporary hospice care: the sequestration of the unbounded body and 'dirty dying'. *Sociology of Health & Illness*, 20(2), 121-143.

- Little, M., Jordens, C. F., Paul, K., Montgomery, K., & Philipson, B. (1998). Liminality: a major category of the experience of cancer illness. *Social Science & Medicine*, 47(10), 1485-1494.
- Macdonald, S., Maxwell, M., Wilson, P., Smith, M., Whittaker, W., Sutton, M., & Morrison, J. (2012). A powerful intervention: general practitioners' use of sickness certification in depression. *BMC Family Practice*, 13(1), 1-9.
- Macleod, U., Ross, S., Twelves, C., George, W. D., Gillis, C., & Watt, G. C. (2000). Primary and secondary care management of women with early breast cancer from affluent and deprived areas: retrospective review of hospital and general practice records. *BMJ: British Medical Journal*, 320(7247), 1442.
- Maddams, J., Brewster, D., Gavin, A., Steward, J., Elliott, J., Utley, M., & Møller, H. (2009). Cancer prevalence in the United Kingdom: estimates for 2008. *British Journal of Cancer*, 101(3), 541-547.
- Mallinger, J. B., Griggs, J. J., & Shields, C. G. (2005). Patient-centered care and breast cancer survivors' satisfaction with information. *Patient education and counseling*, 57(3), 342.
- Manderson, L. (2005). Boundary breaches: the body, sex and sexuality after stoma surgery. *Social Science & Medicine*, 61(2), 405-415.
- Marijnen, C. A., Van De Velde, C. J., Putter, H., Van Den Brink, M., Maas, C. P., Martijn, H., ... & Stiggelbout, A. M. (2005). Impact of short-term preoperative radiotherapy on health-related quality of life and sexual functioning in primary rectal cancer: report of a multicenter randomized trial. *Journal of clinical oncology*, 23(9), 1847-1858.
- Marshall, M. N. (1996). Sampling for qualitative research. *Family practice*, 13(6), 522-526.
- Mays, N., & Pope, C. (2000). Qualitative research in health care: Assessing quality in qualitative research. *BMJ: British Medical Journal*, 320(7226), 50.
- McArdle, C. (2000). ABC of colorectal cancer: effectiveness of follow up. *BMJ: British Medical Journal*, 321(7272), 1332.
- McCaughan, E., Prue, G., Parahoo, K., McIlfatrick, S., & McKenna, H. (2011). Exploring and comparing the experience and coping behaviour of men and women with colorectal cancer at diagnosis and during surgery. *Journal of Advanced Nursing*, 67(7), 1591-1600.
- Mikkelsen, T. H., Søndergaard, J., Jensen, A. B., & Olesen, F. (2008). Cancer rehabilitation: psychosocial rehabilitation needs after discharge from hospital? A qualitative interview study. *Scandinavian journal of primary health care*, 26(4), 216-221.

- Mikkelsen, T., Sondergaard, J., Sokolowski, I., Jensen, A., & Olesen, F. (2009). Cancer survivors' rehabilitation needs in a primary health care context. *Family practice*, 26(3), 221-230.
- Miles, M. B., & Huberman, A. M. (1984). *Qualitative data analysis: A sourcebook of new methods*. London: Sage.
- Miller, L. E. (2012). Sources of uncertainty in cancer survivorship. *Journal of Cancer Survivorship*, 6(4), 431-440.
- Mishel, M. H. (1988). Uncertainty in illness. *Journal of Nursing Scholarship*, 20(4), 225-232.
- Mishel, M. H. (1990). Reconceptualization of the uncertainty in illness theory. *Journal of Nursing Scholarship*, 22(4), 256-262.
- Mishel, M. H. (1999). Uncertainty in chronic illness. *Annual review of nursing research*, 17(1), 269-294.
- Mishel, M. H., Belyea, M., Germino, B. B., Stewart, J. L., Bailey, D. E., Robertson, C., & Mohler, J. (2002). Helping patients with localized prostate carcinoma manage uncertainty and treatment side effects. *Cancer*, 94(6), 1854-1866.
- Moene, M., Bergbom, I., & Skott, C. (2006). Patients' existential situation prior to colorectal surgery. *Journal of Advanced Nursing*, 54(2), 199-207.
- Moustakas C (1994). *Phenomenological Research Methods* Thousand Oaks, California, Sage.
- National Cancer Action Team (2010) *Quality in Nursing, Excellence in Cancer Care: The Contribution of the Clinical Nurse Specialist*. Department of Health.
- National Institute for Health and Clinical Excellence.(2004). *Improving outcomes in colorectal cancers: manual update*. London: NICE.  
<http://www.nice.org.uk/nicemedia/live/10895/28832/28832.pdf> (accessed 26 November 2012)
- Nekhlyudov, L. (2009). "Doc, should I see you or my oncologist?" A primary care perspective on opportunities and challenges in providing comprehensive care for cancer survivors. *Journal of Clinical Oncology*, 27(15), 2424-2426.
- Northouse, L. L., Mood, D., Templin, T., Mellon, S., & George, T. (2000). Couples' patterns of adjustment to colon cancer. *Social science & medicine*.
- Northouse, L. L., Schafer, J. A., Tipton, J., & Metivier, L. (1999). The concerns of patients and spouses after the diagnosis of colon cancer: a qualitative analysis. *Journal of Wound Ostomy & Continence Nursing*, 26(1), 8-17.



Ohlsson-Nevo, E., Andershed, B., Nilsson, U., & Anderzén-Carlsson, A. (2012). Life is back to normal and yet not-partners' and patient's experiences of life of the first year after colorectal cancer surgery. *Journal of clinical nursing*, 21(3-4), 555-563.

Parkin, D. M., Boyd, L., & Walker, L. C. (2011). 16. The fraction of cancer attributable to lifestyle and environmental factors in the UK in 2010. *British journal of cancer*, 105, S77-S81.

Pascoe, S. W., Neal, R. D., Allgar, V. L., Selby, P. J., & Wright, E. P. (2004). Psychosocial care for cancer patients in primary care? Recognition of opportunities for cancer care. *Family practice*, 21(4), 437-442.

Patton, M. Q. (1990). *Qualitative evaluation and research methods*. California: Sage.

Persson, E., & Hellström, A. L. (2002). Experiences of Swedish men and women 6 to 12 weeks after ostomy surgery. *Journal of Wound Ostomy & Continence Nursing*, 29(2), 103-108.

Phipps, E., Braitman, L. E., Stites, S., & Leighton, J. C. (2008). Quality of life and symptom attribution in long-term colon cancer survivors. *Journal of evaluation in clinical practice*, 14(2), 254-258.

Pope, C., Ziebland, S., & Mays, N. (2000). Qualitative research in health care: Analysing qualitative data. *BMJ: British Medical Journal*, 320(7227), 114.

Ramsey, S. D., Andersen, M. R., Etzioni, R., Moinpour, C., Peacock, S., Potosky, A., & Urban, N. (2000). Quality of life in survivors of colorectal carcinoma. *Cancer*, 88(6), 1294-1303.

Renehan, A. G., Egger, M., Saunders, M. P., & T O'Dwyer, S. (2002). Impact on survival of intensive follow up after curative resection for colorectal cancer: systematic review and meta-analysis of randomised trials. *BMJ: British Medical Journal*, 324(7341), 813.

Rozmovits, L., & Ziebland, S. (2004). Expressions of loss of adulthood in the narratives of people with colorectal cancer. *Qualitative health research*, 14(2), 187-203.

Rozmovits, L., Rose, P., & Ziebland, S. (2004). In the absence of evidence, who chooses? A qualitative study of patients' needs after treatment for colorectal cancer. *Journal of health services research & policy*, 9(3), 159-164.

Sahay, T. B., Gray, R. E., & Fitch, M. (2000). A qualitative study of patient perspectives on colorectal cancer. *Cancer Practice*, 8(1), 38-44.

Sammarco, A. (2003). Quality of life among older survivors of breast cancer. *Cancer nursing*, 26(6), 431-438.

- Sanchez, K. M., Richardson, J. L., & Mason, H. R. (2004). The return to work experiences of colorectal cancer survivors. *AAOHN journal: official journal of the American Association of Occupational Health Nurses*, 52(12), 500.
- Sandelowski, M. (1995). Sample size in qualitative research. *Research in nursing & health*, 18(2), 179-183.
- Savatta, S. G., & Temple, L. K. (2005). Quality of life in patients treated for curable rectal cancer. In *Seminars in Colon and Rectal Surgery* (Vol. 16, No. 3, pp. 170-180).
- Schulte, A. (2002). Consensus versus disagreement in disease-related stigma: A comparison of reactions to AIDS and cancer patients. *Sociological Perspectives*, 45(1), 81-104.
- Scottish Intercollegiate Guideline Network. (2003). Management of colorectal cancer: guidelines (SIGN 67). Edinburgh: SIGN.  
<http://www.sign.ac.uk/guidelines> (accessed 26 November 2012)
- Seidman, I. (1998). *Interviewing as qualitative research: A guide for researchers in education and the social sciences*. New York: Teachers college press.
- Shaha, M., & Lynn Cox, C. (2003). The omnipresence of cancer. *European Journal of Oncology Nursing*, 7(3), 191-196.
- Shaha, M., Cox, C. L., Talman, K., & Kelly, D. (2008). Uncertainty in breast, prostate, and colorectal cancer: implications for supportive care. *Journal of Nursing Scholarship*, 40(1), 60-67.
- Sharpe, M., Strong, V., Allen, K., Rush, R., Postma, K., Tulloh, A., ... & Cull, A. (2004). Major depression in outpatients attending a regional cancer centre: screening and unmet treatment needs. *British Journal of Cancer*, 90(2), 314-320.
- Shipman, M. (1988) *The Limitations of Social Research*, (3rd Edition). London: Longman.
- Silverman, D. (2001). *Interpreting qualitative data: methods for analysing talk, text and interaction*. 2nd edition. London: Sage
- Simpson, M. F., & Whyte, F. (2006). Patients' experiences of completing treatment for colorectal cancer in a Scottish District General Hospital. *European Journal of Cancer Care*, 15(2), 172-182.
- Sisler, J. J., Taylor-Brown, J., Nugent, Z., Bell, D., Khawaja, M., Czaykowski, P., ... & Ahmed, S. (2012). Continuity of care of colorectal cancer survivors at the end of treatment: the oncology-primary care interface. *Journal of Cancer Survivorship*, 6(4), 468-475.

- Snape, D. & Spencer, L. (2003) The foundations of qualitative research. In: Ritchie, J. and Lewis, J., (eds). *Qualitative research practice: a guide for social science students and researchers*. ( pp. 1-23). London: SAGE.
- Sontag S. *Illness as Metaphor*. (1978). New York: Farrar, Straus & Giroux.
- Spiegel, D., & Giese-Davis, J. (2003). Depression and cancer: mechanisms and disease progression. *Biological psychiatry*.
- Sprangers, M. A., Taal, B. G., Aaronson, N. K., & Te Velde, A. (1995). Quality of life in colorectal cancer. *Diseases of the colon & rectum*, 38(4), 361-369.
- Sprangers, M. A., Velde, A. T., Aaronson, N. K., & Taal, B. G. (1993). Quality of life following surgery for colorectal cancer: a literature review. *Psycho-Oncology*, 2(4), 247-259.
- Starks, H., & Trinidad, S. B. (2007). Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative Health Research*, 17(10), 1372-1380.
- Taylor, C. (2001). Patients' experiences of 'feeling on their own' following a diagnosis of colorectal cancer: a phenomenological approach. *International journal of nursing studies*, 38(6), 651-661.
- Taylor, C., Richardson, A., & Cowley, S. (2010). Restoring embodied control following surgical treatment for colorectal cancer: A longitudinal qualitative study. *International journal of nursing studies*, 47(8), 946-956.
- Turner, D., Adams, E., Boulton, M., Harrison, S., Khan, N., Rose, P., ... & Watson, E. K. (2013). Partners and close family members of long-term cancer survivors: health status, psychosocial well-being and unmet supportive care needs. *Psycho-Oncology*, 22(1), 12-19.
- Weerakoon, P. (2001). Sexuality and the Patient with a Stoma. *Sexuality and Disability*, 19(2), 121-129.
- Weisman, A. D., & Worden, J. W. (1976). The existential plight in cancer: significance of the first 100 days. *The international journal of psychiatry in medicine*, 7(1), 1-15.
- Wilkinson, S., & Kitinger, C. (2000). Thinking differently about thinking positive: a discursive approach to cancer patients' talk. *Social Science & Medicine*, 50(6), 797-811.
- Williams, S. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health & Illness*, 22(1), 40-67.

Worster, B., & Holmes, S. (2008). The preoperative experience of patients undergoing surgery for colorectal cancer: a phenomenological study. *European Journal of Oncology Nursing*, 12(5), 418-424.

Worster, B., & Holmes, S. (2009). A phenomenological study of the postoperative experiences of patients undergoing surgery for colorectal cancer. *European Journal of Oncology Nursing*, 13(5), 315-322.

Wright, E. P., Kiely, M. A., Lynch, P., Cull, A., & Selby, P. J. (2002). Social problems in oncology. *British journal of cancer*, 87(10), 1099-1104.

Ziebland, S., & McPherson, A. (2006). Making sense of qualitative data analysis: an introduction with illustrations from DIPEX (personal experiences of health and illness). *Medical education*, 40(5), 405-414.