Restoring a sense of wellness following colorectal cancer: a grounded theory

BY

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Nicola Beech

5th December 2010

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Abstract

Aim: This study aimed to develop a grounded theory to explain the experience of recovery following surgery for colorectal cancer.

Background: Studies have adopted a biomedical framework to measure quality of life and symptom distress scores following surgery for colorectal cancer. These studies suggest physical symptoms of pain, insomnia and fatigue may persist for many months following treatment. Fewer studies have considered the individual's experiences and perspectives of the emotional, social and cultural aspects of recovery.

Methods: A longitudinal study using grounded theory was conducted with 12 individuals, who had received surgery for colorectal cancer. Semi-structured interviews were conducted at 4 time points over one year following surgery, between 2007 and 2009. Grounded theory analysis was undertaken using Strauss and Corbin's framework.

Findings: Recovery is described in three phases: disrupting the self; repairing the self; restoring the self. The core category is *Restoring a sense of wellness*; fostered through awareness and enjoyment of the physical, emotional, spiritual and social aspects of life. A sense of wellness exists as a duality with a sense of illness, where both perspectives may co-exist but one usually taking precedence. A sense of illness pervades when the individual is preoccupied with illness and the illness continues to disrupt their daily life.

Conclusion: Recovery takes time and energy, particularly when the individual is at home and in relative isolation from health professionals. Opportunities exist for nurses to provide information and support to facilitate the individual in their progress towards achieving a sense of wellness.

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I would like to dedicate this thesis to my family: John, Brishen, Ethan, Frank and Kathleen. They have shown great tolerance and a never ending conviction that this project would be finished, for which I am indebted.

CHAPTER 1: INTRODUCTION

1.1 Introduction

This study evolved through the taught elements of the Clinical Doctorate programme, culminating in the thesis presented in the following chapters. This introduction chapter begins to build the justification for the study and provides an overview of the thesis. My clinical credentials are presented, followed by the contextual background and clinical origins for undertaking this study. Methodological issues pertinent to the research question will be briefly discussed and an outline of the chapters provided.

1.2 The researcher

I have a clinical background within the field of oncology, and specifically palliative care. At the outset of the Doctorate programme I was working for a voluntary cancer organisation undertaking projects to evaluate information services and working as an information officer. The information service was mobile and travelled across the South East of England, offering a drop in service. Members of the general public would call in, seeking information for themselves or on behalf of another. Comments by the visitors suggested that whilst some individuals had received information during their hospital treatment, many had limited opportunities to access information following discharge from secondary health services. Individuals continued to have information needs and unresolved issues regarding aspects of their illness and treatment. Most were unaware of local or national information services and welcomed the opportunity to talk about their experiences and receive information pertinent to them.

To begin exploring this anecdotal evidence, I conducted a service development project (SDP): Accessing health information (see part II). Representatives from a cancer user group were invited to participate in a focus group or communicate their opinions via email. Their views were sought regarding provision and accessibility of information services in addition to the application of information within the cancer treatment pathway. Respondents indicated they wanted information tailored to their needs, which varied throughout their treatment pathway. Many commented they had limited opportunity to access information outside of contact with secondary health services.

1.3 Background to the study

1.3.1 Political and legislative context

This study was undertaken at a time when the Labour Government was arguing that the National Health Service (NHS) required significant modernisation to meet the present and future demands for health care. The opening statement from the first critical White Paper entitled "The NHS Plan: a plan for investment, a plan for reform" stated that:

"The purpose and vision of this NHS Plan is to give the people of Britain a health service fit for the 21st Century: a health service designed around the patient" (Department of Health (DH) 2000a:1).

Labour's modernisation programme for public services incorporated three broad principles including: the decentralisation of power from central Government to a local level; more autonomy and power to the public to involve them in choices and decisions; and the development of partnerships between service providers and recipients of

services. In a review of long term health care trends, the Wanless Report (DT 2002) identified the most significant determinant of future health costs as the extent to which the public were engaged in modifying their own health-related behaviours. This finding has served as a strong influence for the changing legislative and social focus upon people acting in partnership with health care providers, and taking more personal responsibility for their health behaviour and use of health services (DH 2000b, 2001a, 2001b, 2004a). The wide-spread advocacy of partnerships as an essential requisite of health service reform continued, despite a lack of evidence to support the view that partnerships produced successful outcomes for staff, users, financial sponsors and other stakeholders (Dowling et al 2004).

1.3.2 Information provision

The Labour Government stated that a culture change was required to make services responsive to people's needs, involving a decentralisation of power to put "patients in control" (DH 2003:5). Fundamental to achieving this was the "extension of patient information, power and choice" (DH 2003:6). Government policy explicitly identified the provision of information as a pre-requisite for users of services to become powerful, autonomous and decisive about their health care (DH 2001a, DH 2004a). The Expert Patient report outlined user-led self management programmes to enhance people's ability to self manage their own health care (DH 2001b). In order to achieve this, people required access to as much timely and understandable information as they needed, at any stage, and in an appropriate format (NHS Modernisation Agency 2004). A national consultation on choice, equity and responsiveness identified that people wanted improvements in the quality and accessibility of information (DH 2003). Respondents specifically wanted the right information at the right time, suited to their personal needs.

Almost 90% wanted more information to make decisions and choices about their treatment and care (DH 2003:7).

1.4 *Summary of the research problem*

Much attention has been placed upon the role of information provision throughout the disease trajectory for the individual with cancer. The common belief is that the provision of reliable and comprehensive information can have a positive impact on the individual's experiences (DH 2004b). However, there are several issues which require further consideration. Modern advances in diagnostics and treatment have led to many individuals experiencing cancer as an acute illness, where diagnosis and treatment is rapid, and hospital admissions are of short duration. These individuals are then routinely monitored via follow up outpatient appointments, where limited resources restrict the amount of contact they have with health professionals. Consequently they manage much of their recovery phase independently. The aim of this study is to explore the recovery experience of individuals after completion of surgery for colorectal cancer. A secondary aim is to consider issues of health information provision for this group of individuals.

1.5 *Overview of chapters and methodological issues*

1.5.1 Literature review

Chapter 2 presents the preliminary literature to provide the context and current knowledge for the study. Grounded theory requires the researcher to postpone the substantial literature review until data analysis is well underway and the core category has been identified (Glaser 1992). This issue is discussed in detail in chapter three. The

preliminary literature review was carried out to ensure no similar studies had been reported, to provide focus for the study, and as a requirement of ethical review. As data analysis continued and themes emerged, the literature was continuously reviewed and integrated into the analysis (chapter 4) and discussion (chapter 5).

1.5.2 Methodology and methods

Chapter 3 provides a detailed rationale for my choice of methodology, grounded theory. I was aware that little research had been conducted in the topic of recovery from colorectal surgery for cancer and felt a qualitative approach was most appropriate. I was interested in the social processes and actions of the individual as they recovered from acute surgery. I particularly wanted to explore the individual's experiences over time and needed a methodology which would facilitate a longitudinal exploratory study. Theoretical sampling was employed and focused on those receiving surgery alone for colorectal cancer. Individuals with breast cancer or prostate cancer were discounted as gender specific; the lung cancer group were discounted because of the multiplicity of treatment frequently required in this group. Colorectal cancer is the most prevalent cancer affecting men and women equally; surgery is the definitive treatment; and it was an unfamiliar clinical topic to me. I therefore had less preconceived ideas or knowledge to influence my interpretation of the data. Imposing previous held views or ideas on the topic of research can hinder the emergence of issues from the data (Glaser 1992).

Initially, I aimed to interview the individual immediately following discharge from hospital and before their next outpatient appointment at three months. However early data analysis indicated participants had ongoing needs which were not resolved at three months and therefore a substantial amendment was submitted to the ethics committee. I

decided to increase the length and number of interviews to a maximum of four per participant, over a 12 month period. A total of 12 participants entered the study between January 2007 and January 2010 and completed face to face interviews.

1.5.4 Analysis

Chapter 4 introduces the data analysis, conducted according to the recommendations by Strauss and Corbin (1990; 1998). A reflexive journal and researcher's log was kept throughout data collection and analysis to enhance rigour and aid the inductive analytical process (see part I). Methodological rigour was monitored through the supervision process and reading the literature. Analysis revealed recovery to be an ongoing process where the individual aimed to restore a feeling of wellness. The grounded theory which emerged inductively from the data is *Restoring the Self: a Sense of Wellness*.

1.5.5 Discussion

Chapter 5 presents the discussion of the study findings. The main literature review was conducted once the core category had emerged and is referenced throughout. Chapter 6 concludes the study and makes recommendations for informing clinical practice and future research. The limitations of the study are discussed.

1.6 Summary of chapter

This introductory chapter has presented the rationale for this study by providing an overview of the context and background to the study. My clinical experiences have been described to illustrate how my research ideas evolved from my observations within

practice. The key methodological considerations have been identified alongside an outline of the chapters.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter presents an overview of the supporting literature for this study. The review summarises the current incidence and treatment of colorectal cancer. Studies evaluating quality of life after treatment are presented, followed by research exploring the patient's experience. Key texts from chronic illness literature are reviewed to inform and illustrate a broader patient focused approach to the illness experience. The limitations of current knowledge are described to highlight the rationale for this study.

2.2 Search strategy

Electronic and hand searches were conducted using databases at the University library; the Royal College of Nursing; and Kings Fund, London. Searches were undertaken using medical, nursing and sociology dictionaries; thesaurus; library catalogues and theses. Boolean operators were used with the key search terms of colorectal or bowel cancer. Initially the search terms included information/ communication but as data analysis began and themes began to emerge, search terms were broadened to include aspects of recovery and illness experience (see Appendix A for details). Initial search returns included a vast numbers of articles and the titles were reviewed for eligibility. Articles which reported randomised controlled trials of adjuvant therapies were discarded. All abstracts were reviewed and the full text retrieved for those considered relevant to the study. Key articles were marked for notification of future citations.

2.3 *The burden of colorectal cancer*

Colorectal cancer represents a significant disease burden worldwide, with 1.23 million new cases of colorectal cancer diagnosed in 2008 (International Agency for Research on Cancer (IARC) 2010 online). Almost 60% of these new cases occur in developed regions, with 333 330 diagnosed within the European Union (EU) in 2008 (Ferlay et al 2010). The UK figures for colorectal cancer are below the EU average, with 38 608 new cases in 2007 (Office for National Statistics (ONS) 2010 online). Colorectal cancer is the third most prevalent cancer in the UK, accounting for thirteen percent of all new diagnoses and approximately 106 new cases each day (CRUK 2010a online; IARC 2010 online). Around two-thirds (24,274) of disease occurs in the colon and one-third (14,334) in the rectum (CRUK 2010b online).

Age is a strong predictor for cancer with UK citizens having a 26% risk of developing cancer before the age of 75 years (IARC 2010 online), and 84% of cases of large bowel cancer diagnosed in people who are 60 years or older (ONS 2010 online). Men are more likely to be diagnosed with colorectal cancer and have a lifetime risk of 1 in 16, compared to 1 in 20 for women (CRUK 2010b online). Personal risk of developing colorectal cancer is increased by a familial history (Noe et al 2007). Meta analysis studies suggest a pooled risk estimate (95% CI) for individuals with at least one first degree relative diagnosed with colorectal cancer of 2.24 (2.06 - 2.43) (Butterworth et al 2006); 2.25 (2.00 - 2.53) (Johns & Houlston 2001); and 2.26 (1.86 - 2.73) (Baglietto et al 2006). The risk estimate increases to 4.25 (95% CI = 3.01-6.08) if more than one relative is affected (Johns & Houlston 2001). If the relative is younger than 45-50 years of age at diagnosis the relative risk is increased to 3.87 (95% CI, 2.40-6.22) (Johns & Houlston 2001), or 5.37 (95% CI, 1.98 to 14.6) according to Fuchs et al (1994). This study was

conducted in the South East of England where average standardised incidence rates from 1999 to 2003 was 49.3 per 100 000 for males and 34.6 per 100 000 for female (Hughes et al 2006).

Despite improvements in treatment and survival rates, colorectal cancer is estimated to have caused at least 600 000 deaths worldwide in 2008, with more than half of these deaths in developed regions (IARC 2010 online). Mortality rates in the EU are decreasing (Fernandez 2005), but deaths for 2008 are estimated at 148,000 (Ferlay et al 2010). UK deaths for 2008 totaled 16,259, comprising 10,164 from colon and 6,095 from rectal cancer (ONS 2010 online). The average standardised mortality rate in the South East of England region between 1999 and 2003 was 22.5 per 100 000 for males and 14.8 per 100 000 for females (Hughes et al 2006).

Due to improvements in treatment, it is estimated there are 250 000 people alive with a diagnosis of colorectal cancer (CRUK 2010b online). Five year survival rates have risen for both men and women to approximately 50% for colon cancer and 53% for rectal cancer, in the mid 2000s (ONS 2010 online). Survival rates for ten years are only marginally lower indicating that most patients who survive for five years are cured from this disease (ONS 2010 online).

More than 90% of colorectal cancers develop from adenomas (polyps) which undergo malignant changes (Midgeley & Kerr 1999). Only 10% of adenomas become malignant after 10 years (Scholefield 2000). The incidence of polyps increases with age, most are asymptomatic and often multiple. Flat adenomas are more difficult to detect at endoscopy and account for roughly 10% of all polyps. They may have a higher rate of malignant change or may predispose to a more aggressive cancer phenotype (Hardy et al 2000).

Accurate pathological staging is essential for correct management and the most accurate predictor of prognosis for patients with colorectal cancer is the extent of invasion of tumour through the bowel wall, referred to as TNM staging (Treanor & Quirke 2007) (see Appendix B for table of TNM staging). The left side of the bowel is more commonly affected by cancer: tumours in the sigmoid colon, rectosigmoid junction and the rectum together account for over half of all cases (CRUK 2010b online). See Appendix B for the anatomy and diagram of the large bowel.

2.4 *Surgical treatment for colorectal cancer*

Surgery remains the definitive treatment for localised colorectal cancer, with right sided cancer treated by right hemicolectomy and left sided cancer by left hemicolectomy or sigmoid colectomy as appropriate (Leslie & Steele 2002). In recent years, laparoscopic techniques are being widely adopted as surgery of choice and are now recommended as an alternative to open surgery (NICE 2006). Laparoscopic surgery (LS) has previously demonstrated advantages in the treatment of benign disease, and is now being considered with regards to malignant disease (Cera & Wexner 2005). Despite a lengthier time in surgery (Lezoche et al 2002), LS results in a shorter hospital stay (Bilimoria et al 2008; Kennedy et al 2009), a decreased risk of postoperative complications in the elderly (Kennedy et al 2009), with less wound and pain problems post operatively (Franklin et al 1996; Veldkamp et al 2004). Patients are more satisfied with the cosmetic result of the scar (Dunker et al 2001), and experience a quicker return to full activity and normal bowel function (Lacy et al 2002; Veldkamp et al 2004). No differences between rates of survival, disease recurrence or death have been noted between LS and open surgery after five years (Kuhry et al 2008; Lezoche et al 2002).

Surgical techniques for rectal cancer emphasize sphincter-saving techniques and the avoidance of a permanent stoma where possible (DeSnoo & Faithfull 2005). Surgery aims to minimise damage to the pelvic nerves (Leslie & Steele 2002). It is accepted that a shorter margin between the tumour and normal bowel tissue does not compromise the rate of local recurrence whilst also allowing anastomosis for lower tumours and avoiding the need for a stoma (DeSnoo & Faithfull 2005). There is growing evidence that minimally invasive laparoscopic surgery is also favourable for the treatment of rectal cancer (Strohlein et al 2008).

2.5 Recovery following treatment for colorectal cancer

Studies evaluating the impact of treatment for colorectal cancer have predominantly used quantitative methodology to measure quality of life (QoL), symptoms, activities of daily living and functional activity. Studies have included patients within the acute phase of illness, including treatment and immediately post treatment and also the chronic phase for several years after completing treatment. Table 1 summarises the studies reviewed in the following section. Comparison between the studies is complex because of variation in methodology including: the purpose or aim of study; sample size and type; disease diagnosis and staging; treatment modalities; measurement tools and time of administration. Several studies have presented single, cross sectional data. Other studies have adopted a pre and post design with a minimum of two data collection points.

2.5.1 The immediate post treatment phase

Whelan et al (1997) examined the emotional and physical needs of 134 cancer patients after they had received a confirmed cancer diagnosis and were attending an outpatient

appointment in a regional centre providing adjuvant treatment. The patient sample was predominantly breast, lung and prostate cancer patients, with a very small number of colorectal patients (n=10, 7%). Patients reported high information needs regarding disease and treatment information. Patients also raised concerns regarding their general health, although the authors comment a limitation within their study was a failure to systematically record co-morbidity. Specific symptoms causing moderate distress were fatigue (64%) and insomnia (46%). Galloway and Graydon (1996) evaluated patients' experiences pre and one month post surgery. They included 40 colorectal cancer patients and found low scores for symptom distress with regards to fatigue and pain, however, the sample had moderate scores for uncertainty. Uncertainty was associated with an increased need for discharge information needs relating to activities of daily living and enhancing QoL.

2.5.2 Three months following treatment

Several authors have considered aspects of QoL at diagnosis of colorectal cancer and three months later. Pan et al (2010) were solely concerned with measuring diarrhoea distress and self care practices at monthly intervals for three months. They recruited 35 colorectal cancer patients with all stages of disease, receiving surgery alone. Their results indicated that diarrhoea gradually subsided over three months from surgery and that younger patients were more likely to adopt self care practices, such as dietary modification. Whynes and Neilson (1997) assessed QoL in 49 colorectal cancer patients. Half had early stage disease and all received surgery only. Symptoms which improved by three months included appetite, worry, anxiety and bleeding from the back passage. Symptoms presenting significant problems included: flatus (13%); tiredness (12%); lack of energy (14%) and difficulty sleeping (14%). Some symptoms had not been

problematic pre surgery although the sample size was small and details of age were not clarified (see table 1).

Hodgson and Given (2004) included 172 cancer patients with early stage disease, receiving surgery only. Forty (23%) had colorectal cancer. At 3 months post surgery, fatigue and pain were reported by over half of patients, although symptom scores were low. Higher levels of symptom severity were associated with co-morbidity and a decreased return of functional recovery, although figures are not provided which makes verification problematic. Esbensen et al (2006) included 85 cancer patients with all stages of disease, including 22 (26%) colorectal patients. Treatment modality was not disclosed and figures were not provided, although Esbensen et al (2006) comment that commonly reported symptoms included fatigue, insomnia and pain.

2.5.3 Six months following treatment

Ulander et al (1997) compared QoL and activities of daily living pre and 6 months post treatment for 86 colorectal cancer patients; Bailey et al (2006) evaluated the impact of treatment on functional status and service use, pre and 6 months post treatment for 337 colorectal cancer patients. Both studies included patients with all stages of disease and all treatment modalities. Ulander et al (1997) included a diverse range of ages; while Bailey et al (2006) purposefully selected adults aged 58 and over. Both studies observed an increase in global QoL scores by six months, however, older patients had more significant impairment in health and activity level (Bailey et al 2006) and stoma patients had worse physical and role functioning scores (Ulander et al 1997). Ulander et al (1997) also noted persistent problems with fatigue (76%), sleep disturbance (21%) and diarrhoea (16%).

Table 1: Studies of quality of life, symptoms, activities of daily living and functional ability following treatment for colorectal cancer

Authors	Objective of study	Sample	Measures	Results
Anthony et al (2001)	Determine long term impact of surgery and adjuvant therapy on health related QoL	114 colorectal cancer patients (all stages) Treatment: surgery only (53%); surgery and adjuvant (46%) Benign colorectal disease: surgery (n=44) Age range 41-86 yrs, mean age: benign colorectal 63 yrs, surgery 68.6yrs, surgery + adjuvant 64.8 yrs	SHORT FORM 36; disease specific supplement. T1 - follow up OPA (no time details but at least 6 months post treatment)	Trend towards improved physical health and health related QoL for colorectal patients (both groups) compared to benign group. Authors propose colorectal cancer patients expect different outcomes, resulting in higher optimism regarding QoL.
Armes et al (2009)	Estimate the prevalence and severity of supportive care needs in immediate post treatment phase	1152 cancer patients: breast (n=801, 56%), prostate (n=330, 23%), colorectal (n=127, 9%), gynaecologic (n=90, 6%), non-Hodgkin's lymphoma (n=65, 5%) (all early stage disease) Treatment: chemotherapy/radiotherapy (100%) Mean age 61 yrs	Supportive Care Needs Survey; Health Concerns Questionnaire; Hospital Anxiety Depression Scale; Positive Affect Negative Affect Scale T1 - end treatment, T2 - 6 months later	Overall low incidence of moderate/severe unmet needs: T1 - fear cancer spreading (30%), worries of those close to you (26%), uncertainty future (26%), tiredness (21%). T2 - fear cancer spreading (26%), uncertainty future (20%), tiredness (19%).
Arndt et al (2006)	To assess QoL one and three years after diagnosis	309 colorectal cancer patients (all stages) Treatment: surgery (100%); + radiotherapy (n=68, 22%); + chemotherapy (n=145, 47%) Age range 18-70+ yrs. Mean age 66.1 yrs	EORTC QLQ-C30 T1 - 1 year post diagnosis T2 - 3 years post diagnosis.	At 3 years small decline role, cognitive, social functioning and global QoL; insomnia and dyspnoea worse. Small improvements physical functioning, diarrhoea and financial worries.
Bailey et al (2004)	To evaluate impact of treatment on functional status and service use	337 colorectal cancer patients (all stages) Treatment: surgery only (n=149, 44%); +radiotherapy (n=49, 15%); +chemotherapy (n=71, 21%); palliative/ none (n=68, 20%) Age range 58-95 yrs	OARS Multidimensional Functional Assessment Questionnaire, Rotterdam Symptom Checklist, self reported severity morbidity. T1 - pre treatment, T2 - 6 months after surgery/ 2 months after adjuvant.	Aged 74 or less, reductions in morbidity and psychological distress, improved overall QoL. Aged 75+, increased impairment in mental health and activity level. All ages significant impairment self care capacity: needs at home nursing care (80%); personal care (37%); housework (67%)
Cotrim & Pereira (2008)	To assess impact of colorectal surgery on QoL	153 colorectal cancer patients, 96 informal carers (disease stage not specified) Treatment: surgery (n=43, 28%), +chemotherapy (n=73, 48%), +chemotherapy/radiotherapy (n=34, 22%)	EORTC QLQ-C30/ 38; Index marital satisfaction; Index sexual satisfaction; Body image scale; Hospital Anxiety	Stoma patients: poorer function in physical, role, social, emotional, general health and overall QoL. More symptoms fatigue, diarrhoea, male sexual problems, depression.

		Age range 27-88, mean 64 yrs	Depression Scale. Caregiver Burden assessment scale; Beck depression inventory; STAI. T1 - 6-8 months post surgery	Caregivers of stoma patients had more depression and anxiety.
Deimling et al (2007)	Report fatigue and pain reported by long term older adult survivors cancer	295 cancer patients: breast (n=123, 42%), prostate (n=86, 29%), colorectal (n=86, 29%) (all stages) Treatment: surgery only (n=126, 43%), + radiotherapy (n=36, 12%), + chemotherapy (n=29, 10%), all (n=14, 5%), radiotherapy only (n=24, 8%), other (n=66, 22%) Mean age at diagnosis 62.3yrs Time since diagnosis 5-34 yrs	Symptom indices (21 symptoms); Pain frequency/intensity (Likert 0-4); fatigue energy and weakness (Likert 0-3); Health Conditions Index; Functional Difficulty Scale. T1 - 5+years post treatment.	Patients reporting frequently/ always pain (n=78, 26%); very intense/ unbearable (n=46, 19%). Weakness quite a bit/ very much (n=26, 9%). Correlates for pain and lower energy: African Americans, women, number health conditions, functional difficulty. Pain, energy and weakness significant predictors functional difficulties. Age related factors explained 21% total variance, cancer related factors contributed 6%.
Engel et al (2003)	Assess long term QoL in rectal cancer patients.	320 rectal cancer patients (all stages) Treatment: anterior resection or extirpation surgery only (n=299, 93%), remainder palliative or local resection. Age details not specified	EORTC-30/ 38 T - 1,2,3,4 yrs post treatment.	Generally all scores improved over time except cognitive function and dyspnoea which decreased. Fatigue, stoma problems, weight loss showed little improvement. Stoma patients significantly worse QoL, QoL improved if stoma reversed.
Esbensen et al (2006)	Investigate activities daily living, hope, social network, support and relationship to QoL	85 cancer patients: breast (n=24, 28%), lung (n=18, 21%), gynaecologic (n=21, 25%), colorectal (n=22, 26%) (all stages) Treatment not specified Mean age 75yrs	EORTC QLQ-C30; Nowotny's hope scale; KATZ ADL index; ISSI. T1 contact 1wk after diagnosis; T2 - 3mths post T1.	No significant change global health status/ QoL between T1 and T2. Most common symptoms: fatigue, insomnia, pain (figures not provided). Low level hope, dependency in ADLs, reduced economy associated low level QoL.
Galloway &	Determine relationship between uncertainty,	40 colorectal cancer patients (stage not specified)	Mishel Uncertainty Illness Scale, Visual Analogue	Moderate score for uncertainty, low symptom distress, fatigue most distressing.

Graydon (1996)	symptom distress and discharge information needs	Treatment: surgery (100%) Age range 43-89 yrs, mean 66.2yrs	Scale - fatigue, pain, loss appetite, constipation, diarrhoea, Patient Learning Needs Scale. T1 - 72 hrs pre discharge (4-28 dys post surgery), T2 - 4 wks post discharge.	Moderate information needs pre and post discharge. Information needs related to activities living, treatment and complications, enhancing QoL.
Hodgson & Given (2004)	Examine psychosocial and disease factors influencing functional recovery.	172 patients: prostate (n=67, 39%), breast (n=43, 25%), colon (n=40, 23%), lung (n=22, 13%) (early stage disease) Treatment: surgery only (100%) Age range 65 + yrs, mean 72.5 yrs	SHORT FORM 36. T1 4-6 weeks; T2 14-16 weeks after hospital discharge	Fatigue & pain reported 50%+ patients. Higher symptom severity and co-morbidity associated decreased likelihood functional recovery. Little evidence regarding care giving needs (warrants qualitative evaluation).
Kozachik & Bandeen-Roche (2008)	Explore patterns pain, fatigue and insomnia (PFI) over first year of cancer diagnosis	867 cancer patients: prostate (n=285, 29%); breast (n=234, 27%), lung (n=224, 26%); colorectal (n=153, 18%) (all stages) Treatment: surgery (n=667, 68%), +/or chemotherapy (n=93, 9%), radiotherapy only (n=328, 34%), chemotherapy & radiotherapy (n=129, 13%) Age 65+yrs, mean 72.6yrs	Co-morbidity index, patient symptom experience (37 items). Condensed from Ageing and Health in America. After diagnosis: T1 (6-8 wks), T2 (12-16 wks), T3 (24wks), T4 (52wks)	PFI prevalence peaked T1, steadily decreased time since diagnosis. Prevalence of fatigue T1 (20%), T2 (21%), T3 (21%), T4 (18%) Advancing age not significantly associated increased risks PFI patterns
Pan et al (2010)	To understand changes in and factors influencing diarrhoea distress and self care practices after colorectal cancer surgery.	35 colorectal cancer patients (all stages) Treatment: surgery (100%) All ages	Diarrhoea distress scale developed for study. Interview 1 week, 1, 2 & 3 months post surgery.	Diarrhoea frequency and distress highest one week post, but gradually decreased thereafter. Self care practices increasing in use by 3 months and rated most effective were dietary modification and exercise. Strategies most utilised by younger patients (<50 years).
Ramsey et al (2000)	Survey health related QoL (HRQoL)	173 colorectal cancer patients (all stages) Treatment: not specified Mean age 70.4 yrs	FACT - C, Health Utilities Index Mark III. T1 - 13 - >60 months post diagnosis.	Impact of colorectal cancer on HRQoL is greatest and most varied for first 12-36 months. After 36 months, stabilises at high level except for stage IV patients who continued experience decrease. Functional and social wellbeing changed very little over time from diagnosis.

Schag et al (1994)	To assess QoL in adult survivors lung, colon and prostate cancer.	278 cancer patients: lung (n=57, 21%), colon (n=117, 42%), prostate (n=104, 37%) (all stages) Treatment: not specified Survivors: short term (less 2 years); intermediate (2-5 years); long term (5 years and over) Mean age: lung 62.38 yrs, colon 64.61 yrs, prostate 69.50 yrs	Cancer Rehabilitation Evaluation System; QoL linear analogue scale. T1 - not specified	Colon patients: overall QoL improved. Proportion colon survivors at all time periods with frequent/ severe problems: reduction energy (61%), difficult physical activity (50%), no interest recreational activity (48%), difficulty sleeping (52%), difficulty remembering (45%), nervous waiting test results (57%), worry whether cancer progressing (47%), worry family manage if die (47%).
Steinga et al (2009)	Prospective study of medical, socio-demographic, psychosocial and lifestyle variables in QoL outcomes	1822 colorectal cancer patients (all stages) Treatment: surgery only (n=984, 54%), temporary or permanent stoma (n=310, 17%) Age range 20-80 yrs, mean age 65 yrs	Telephone interview; FACT-C version 4. T1 - 6 months; T2 - 24 months post diagnosis	Higher QoL at 24 months predicted by 6 month QoL scores Higher QoL at 24 months associated with lower cancer appraisal score; higher optimism and less co-morbidity. Low levels social wellbeing linked poor social support and lack faecal control.
Trentham-Dietz et al (2003)	To describe overall health related QoL of female long-term colorectal cancer patients	307 women with colorectal cancer (all stages) Treatment: not specified. Age range 43-85, mean age 72 yrs	Medical Outcomes Study Short Form 36. T1 - 7-11 years post diagnosis, mean 9 yrs	Lower physical component summary score associated with older age, co-morbidity and greater body mass index. Lower mental component score associated with co-morbidity. Ageing, body weight, chronic medical conditions more important in determining physical and mental health than cancer.
Ulander et al (1997)	To describe QoL domains and independence ADLs	86 colorectal cancer patients (all stages) Treatment: surgery (100%), + pre operative radiotherapy (n=21, 24%), +chemotherapy (n=10, 12%) Age range 19-90 years, mean age 70 yrs	EORTC QLQ-C30, Katz Index Independence. T1 - pre surgery, T2 - 5-8 months post surgery.	T2 improvements: emotional, cognitive, social functioning, global QoL. Rectal patients significantly lower scores physical and role functioning scales. Colon patients significantly improved scores emotional functioning, less pain and constipation. Persistent problem symptoms at T2 included fatigue (76%), sleep disturbance (21%), diarrhoea (16%).
Whelan et al (1997)	Examine physical and emotional health status,	134 cancer patients: breast (n=28, 21%), colorectal (n=10, 7%), head and neck	Symptom Distress Scale; General Health	Symptoms causing moderate distress: fatigue (64%), outlook (57%), insomnia

	self perceived problems and needs/	(n=23, 17%), lung (n=27, 20%), prostate (n=26, 19%), skin (n=20, 15%) (all stages) Treatment not specified Mean age 63.2yrs	Questionnaire: Rapid Disability Scale; Sarason Social Support Questionnaire; open ended questions. T1 - newly diagnosed, pre Outpatient Appointment	(46%). Low reported needs regarding day to day activities living. 65% reported social concern: ability look attractive (37%), maintain friendships (36%). Most important problem: health (43%), family (26%), emotional (11%). 85% specific information needs: treatment information (63%), disease related (56%).
Whynes & Neilson (1997)	Assess QoL patients undergoing surgery for colorectal cancer.	49 colorectal cancer patients (half early stage disease) Treatment: surgery only (100%) Age details not specified	Nottingham health profile; Rotterdam Symptom Checklist. T1 - pre surgery; T2 -3 months post surgery.	Improvement by 3 months: appetite; worry; anxiety; bleeding back passage; urgency. Quite a bit/ very much problem at 3 months = flatul (13%), tiredness (12%), lack energy (14%), difficulty sleeping (14%) (tiredness not real problem pre surgery). No global QoL score.

Cotrim and Pereira (2008) also found worse symptoms scores for patients with a stoma. They assessed QoL at six months post surgery in a sample of 153 patients with a mean age of 64 years. One third of patients had ostomy surgery and had lower QoL scores in all domains. Stoma patients also had higher scores compared to non stoma patients for fatigue (mean 49.52 v 38.94 respectively), diarrhoea (mean 35.51 v 23.68 respectively) and male sexual problems (mean 69.89 v 50.98 respectively). Stoma patients had significantly worse role function, body image, general health and overall QoL. They also had a higher prevalence of depression, positively associated with caregiver depression and burden.

2.5.4 Quality of life in the longer term

Kozachik and Bandeen-Roche (2008) specifically explored patterns of pain, fatigue and insomnia during the first year following diagnosis in 867 cancer patients. Their sample included patients with all stages of disease, with just under three quarters having surgery (n=667, 68%) and one third receiving radiotherapy only (n=328, 34%). Symptom prevalence peaked at two months and then steadily declined. They did not provide individual scores for pain and insomnia, but prevalence of fatigue showed little improvement by one year post diagnosis. Co-morbidity, but not advancing age (mean age 72 years) was associated with symptom prevalence and predictors for increased pain, fatigue and insomnia patterns at all time points. Steninga et al (2009) undertook a large survey with 1822 colorectal cancer patients including all stages of disease, treatment modalities and age (mean 65 years). Quality of life scores at six months post diagnosis were predictive for QoL scores at two years. Higher QoL at two years post diagnosis was associated with lower cancer appraisal score, higher optimism and less co-morbidity.

Ramsey et al (2000) suggest the impact of colorectal cancer is greatest within the first 1-3 years following diagnosis, after which QoL stabilises at a higher level. Their survey included 173 colorectal cancer patients with all stages of disease, ranging from 1-5 years post diagnosis. A tendency towards improved QoL over time is also supported by Anthony et al (2001). They compared the impact of treatment on 3 groups of patients including: patients with benign colorectal disease (n=44, 38%); 114 colorectal cancer patients of whom 61 (53%) received surgery and 53 (46%) received surgery and adjuvant treatment. Data were collected at least six months post treatment, with a mean time of 31 months for the benign group, 33 months for the colorectal cancer surgery group, and 32 months for the colorectal cancer surgery and adjuvant group. With a majority of the sample nearly three years post treatment a trend towards improved QoL and physical health was noted.

Studies suggest that quality of life for colorectal cancer patients improves over time following treatment, although some symptoms may persist. Schag et al (1994) recruited 278 cancer patients including 117 with colorectal cancer (42%), varying from less than two years to over 5 years from diagnosis. Overall QoL improved for colorectal cancer patients, however, frequent problems were noted regarding reduced energy (61%), physical activity (50%), difficulty sleeping (52%) and worry whether cancer was progressing (47%). Details are not provided of the data collection interval and the high prevalence of problems may therefore reflect a number of patients closer to the time of diagnosis or treatment. Arndt et al (2006) assessed the QoL of 309 colorectal cancer patients, one year and three years after diagnosis. All patients received surgery and nearly half had adjuvant chemotherapy (n=145, 47%). Only 222 (72%) of the original sample were able to complete the second QoL questionnaire. Most patients reported a high overall QoL three years

after diagnosis, and only small deficits in physical and role functioning when compared with controls from the general population. Scores were worse for emotional and social functioning at three years, as were insomnia, fatigue, dyspnoea, constipation and diarrhoea. The differences between scores for colorectal cancer patients and the general population were largest in younger patients (age <60 years) but differences diminished with age, suggesting some aspect of the symptom experience may be moderated by older age. Deimling et al (2007) proposes that age related factors may have a stronger influence upon long term effects, rather than cancer. Their study of 295 cancer patients at least five years post treatment found that pain and weakness were correlated with the number of health conditions and functional difficulty. Interestingly, their sample was relatively young with a mean age of 62.3 years, although the range of time since diagnosis was 5-34 years and included all stages of disease. It is therefore possible that advanced disease or long term morbidity following treatment may also have influenced the symptom experience. The importance of age related factors are suggested by Trentham-Dietz et al (2003) who found advancing age, co-morbidity and body weight were more important than cancer in determining QoL. Their sample included 307 women, 7-11 years after a diagnosis of colorectal cancer, with all stages of disease and a mean age of 72 years.

Engel et al (2003) conducted a longitudinal study to assess QoL up to four years post treatment for 320 patients with rectal cancer. Their results suggested that the type of surgical operation had an impact upon QoL scores, with stoma patients having significantly worse QoL scores than non stoma patients. Physical symptoms showed little improvement in mean scores over time for fatigue, sleep, diarrhoea and constipation, and mean pain scores showed no change. Role, emotional and social functioning, however, showed improvement over time.

2.5.5 Limitations of quality of life studies

Drawing comparisons between the studies of QoL is complex partly due to their differing aims and data collection techniques. The studies suggest a longitudinal component to symptoms and QoL post treatment, potentiated by advancing age and co-morbidity but the results are ambiguous due to methodological differences. Most studies used validated and reliable data collection tools but sample sizes, diagnosis and disease staging varied. Some studies failed to disclose treatment modalities or age of the sample, which are potentially two factors influencing QoL and symptoms following treatment. Gradual improvements in physical health and QoL were noted in most studies as time passed following treatment, although there was little consistency in the duration and time intervals of data collection. Studies provide evidence of QoL and suggest fatigue, pain and bowel disturbances may persist, but many fail to fully address the psychosocial aspects of the individual's experiences. Armes et al (2009) aimed to estimate the unmet supportive care needs of 1152 cancer patients with early stage disease, who had received chemotherapy and/ or radiotherapy. They argued that QoL measures fail to capture issues pertinent to the patient following treatment and therefore the authors administered a needs assessment tool. Results indicated a low incidence of moderate or severe unmet needs; although fears of cancer spreading and an uncertain future were the most frequently identified unmet need and scores only decreased slightly by six months. Slightly less than one third reported more than five unmet needs on completion of treatment, and for over half, their needs remained unresolved by six months. As Ironside et al (2003) comment, focusing upon functional status alone does not adequately account for the experience of recovery following colorectal cancer surgery.

2.6 *Studies of patient experiences*

Relatively few qualitative studies have been conducted with colorectal cancer populations (Dunn et al 2006). Qualitative studies have varied in purpose and design, although the majority have used semi structured interviews. Differing samples have been recruited, and data collected at different time intervals and frequency. Studies do report some overlap between key themes arising from the data (see table 2).

Worster and Holmes (2009) interviewed 20 newly diagnosed colorectal cancer patients one month after surgery. Patient's experiences were dominated by their physical condition as they passed through a stage of complete dependence and a loss of control and dignity. As physical independence was slowly regained, fear and anxiety developed as the realisation of the cancer diagnosis reoccurred. Some patients were anxious about hospital discharge and leaving the 'safety' of the hospital environment.

Broughton et al (2004) interviewed 49 patients with bowel cancer; the majority of whom had surgery within the previous three months. Eight carers participated in a focus group. Five themes emerged from the data: experience of symptoms; GP management; impact of diagnosis; perceptions of clinical care and treatment; information needs. Overall, patients were generally satisfied with aspects of GP management, diagnosis and clinical care. However, they commented they would have liked more information and opportunity to ask questions at the time of diagnosis. Patients also wanted more information at discharge, particularly regarding expectations of symptoms during recovery. Patients viewed specialist nurses as a main source of written information and support, and commented there was a lack of information in GP surgeries (Broughton et al 2004). Dissatisfaction with the amount

of information regarding the longer term management of their illness was reported by Dunn et al (2006). One to one interviews were conducted with 15 colorectal cancer patients, diagnosed within the previous 18 months. Patients were asked to comment on QoL and psychosocial variables most pertinent to them, and these issues were then discussed within a focus group of patients and carers. A total of six themes emerged: satisfaction with diagnosis and treatment; support (including information provision); QoL; benefits of diagnosis; making sense of the cancer experience; coping strategies. In contrast to Broughton et al (2004), some patients were less satisfied with the process of diagnosis and treatment as they experienced delays in GP referral to secondary care or during investigations. Patients reported information provision was poor and impersonal, specifically mentioning a lack of information regarding diet. Ongoing symptoms of tiredness and weakness led to reduced functioning and social isolation for some (see table 2).

Rozmovits and Ziebland (2004) also comment on the loss of social confidence arising as a consequence of treatment for colorectal cancer. Interviews were conducted with 39 patients, purposefully selected to include all stages of disease and variable time since diagnosis, to consider short and long term consequences of colorectal cancer. Persistent problems with eating and bowel habits prevented a return to pre illness life, creating social isolation. Patients with stomas experienced major psychological problems affecting their sexual identity, including anxiety about physical relationships. Patients without access to a specialist professional felt bereft of support and information. Time offered opportunity for rehabilitation but the authors comment that the distress experienced in response to colorectal cancer is more than simple embarrassment; it is the removal of adult identity and the "Loss of Adulthood". The theme of personal identity and perception of self is also noted by Taylor (2001) in a

study of 8 newly diagnosed colorectal cancer patients. In response to the diagnosis, patients were forced to think of themselves and their relationships with others. The key theme "Feeling on your own" emerged from the data. Patients perceived no one else could appreciate the impact of the diagnosis. A sense of aloneness was created by personal and social difficulties in talking about cancer and the associated fear and embarrassment.

Table 2: Interview studies exploring patient experiences

Authors	Study aim and design	Sample	Data collection and analysis	Results
Broughton et al (2004)	Investigate patient and carers perspectives of care. Qualitative design.	49 colorectal cancer patients; 8 carers (staging not specified) Newly diagnosed. Treatment not specified. Age range 37-91 years, mean 69 years.	One semi-structured interview (n=49 patients), three quarters within 3 months of diagnosis. Focus group (n=8 carers). Fram ework analysis.	Doctor's ability to inspire confidence and provide straightforward explanations was important. Specialist nurses considered main source support and information. 25 patients had stoma but not all saw stoma nurse. Lack information available in GP surgeries. Wanted more information at discharge, particularly about what symptoms are normal after surgery.
Desnoo and Faithful (2005)	To explore the experience of anterior resection syndrome. Grounded theory.	7 rectal cancer patients (staging not specified) Time since diagnosis not specified. Treatment: surgery and stoma reversal at least 6 months previously Age range 60-78 years, mean 71 years.	One semi-structured interview. Constant comparative analysis.	Three categories: adapting to physical changes; psychological adaptation; stigma. Achieving confidence and normality was a fundamental aim of strategies utilized by participants. Physical changes were expected following surgery but symptoms were difficult to control and manage. Unpredictable and irregular bowel function was the predominant problem. Social behaviours were curtailed by unpredictable symptoms.
Dunn et al (2006)	What are most salient dimensions of QOL to patients? Between methods triangulation.	19 colorectal cancer patients; 2 carers (staging not specified). Diagnosed < 18 months. Treatment not specified. Age: under 80 years.	One semi-structured interview (n=15 patients). Focus groups: patient (n=5) carer (n=2). Thematic analysis.	Support received from health professionals, family, friends, but rarely had access to dietician. Information provision was poor, basic and not personalised. Lack information regarding diet. Physical rehabilitation was lengthy, residual problems of weakness and tiredness. Social isolation due to reduced physical function, or avoidance. Positive attitude and clearer perspective on important things in life was helpful.
McVey et al (2001)	To explore the experiences of patients following stoma surgery.	8 cancer patients (staging not specified). Time since diagnosis not specified.	Longitudinal design. Semi-structured interviews: 1-2 weeks pre surgery (n=8), 1-2 weeks	Lowered personal control was experienced as a result of persistent symptoms, diagnosis of cancer and medical procedures. Loss of control was exacerbated by withholding or lack of information,

	Grounded theory.	Treatment: urostomy or colostomy formation. Age: 49-82 years.	post surgery (n=7), 3 months post surgery (n=4).	and mitigated by contact with people who knew about stoma care. Defensive strategies of dismissing fear, over optimism and shock were used pre and post operatively.
Mizuno et al (2007)	Investigate dynamic experience following diagnosis. Inductive inquiry.	12 colorectal cancer patients (all stages) Diagnosed < 6 months. Treatment: surgery. Age range 43-79 years, mean 66.2 years.	Prospective study. Semi-structured interview (n=12 patients, mean 111 days post surgery). Follow up interview one month later (n=5 patients).	Three domains symbolized experiences: types of burdens (vulnerability, lack of control, seeking assistance or support, why questions); steps in accepting cancer diagnosis (learning to be grateful, developing willpower, feeling one is getting better); ways of living a normal life (resisting vulnerability, constructing daily living routine, asking for help). Patients reduced tensions by positively defining and understand their experiences.
Ramfelt et al (2002)	Explore emotional and interactional perspectives in the meaning of illness. Design not specified.	52 colorectal cancer patients (all stages) Newly diagnosed. Treatment not specified. Age range 34-83 years, mean 68 years.	Qualitative analysis. Prospective study, three interviews over 12 months. Constant comparative analysis.	The body and body perception were fundamental to patient's ways of finding meaning in illness. Main theme: attempting to find meaning to achieve emotional coherence. Two dimensions co-existing, no clear boundaries between. Unified embodiment includes gratefulness, confidence in oneself and looking forward to creating future. Dichotomized embodiment includes altered self value, loss temporality and infringement body integrity.
Rozmovits et al (2004a)	Qualitative study patients needs after treatment. Narrative interviews.	39 colorectal cancer patients (all stages). Time since diagnosis not specified. All treatment modalities. Age range 28 to 68 years, mean age at diagnosis 53.9 years; mean age at interview 60.1 years.	One semi-structured interview. Thematic analysis using constant comparison.	Recovery would have been less traumatic if given realistic idea what to expect. 22 patients had experience of stoma (temporary or permanent) Patients received no information of national advisory and support services. Patients without a stoma nurse can feel bereft of support and information. Patients were ambivalent regarding follow up: reassurance for disease surveillance but anxiety waiting for test results. Sense of security and familiarity with GP follow up.
Rozmovits and Ziebland (2004b)	Consider aspects of distress expressed by	39 colorectal cancer patients (all stages).	One semi-structured interview.	Overarching theme of Loss of Adulthood. Sub themes: loss of professional identity; loss of ability

	patients (second component of study above) Narrative interviews.	Time since diagnosis not specified. All treatment modalities. Age range 28 to 68 years, mean age at diagnosis: 53.9 years; mean age at interview 60.1 years.	Thematic analysis using constant comparison.	to socialize; leaning to manage a stoma (loss dignity, privacy and independence); disruption sexual identity.
Shaha and Cox (2003)	To explore meanings of experiences following diagnosis. Phenomenology.	7 colorectal cancer patients (staging not specified) Diagnosed < 6 months. Treatment: surgery. Age not specified.	Prospective study. Multiple semi-structured interviews over one year. Colaizzi's data analysis.	Main category: The omnipresence of cancer. Two sub categories: towards authentic being, mapping out the future. Diagnosis means individual has potential of lifelong illness and death. Individual feels stigmatised by diagnosis. Insufficient information triggered feelings of uncertainty.
Taylor (2001)	To explore the experience of being diagnosed with colorectal cancer. Phenomenology.	8 colorectal cancer patients (staging not specified) Newly diagnosed. Treatment not specified. Age not specified.	One semi-structured interview, within one month of diagnosis. Thematic analysis.	Six themes: making sense of diagnosis; fearing the worst; redefining the future; having to go with the treatment; managing day to day; feeling on your own.
Taylor et al (2010)	To discover the process of recovery following surgery. Grounded theory.	16 colorectal cancer patients (early stage) Newly diagnosed. Treatment: surgery. Age not specified.	Prospective study. Four semi-structured interviews over 12 months. Inductive analysis.	Patients experienced a disconnection with their body and body control is lost. 4 conceptual stages: disembodiment; restoring embodiment; reclaiming control; managing embodied control.
Worster and Holmes (2009)	To investigate patients experience during postoperative phase of recovery. Phenomenology.	20 colorectal cancer patients (staging not specified) Newly diagnosed. Treatment: surgery. Age range 50-82 years.	One semi-structured interview, one month after surgery. Giorgi's analytical steps.	Themes included: relief surgery is over; needing information; loss of dignity; personal appearance; loss control and mobility; inability to eat and drink; lack of sleep; discharge. Patients passed through stage of complete dependence to a degree of renewed independence at discharge.

Mizuno et al (2007) interviewed 12 colorectal cancer patients within six months of diagnosis, and five patients participated in a follow up interview one month later. The experience of diagnosis was symbolized by three domains: types of burden; steps in accepting the cancer diagnosis; and ways of living a normal life. A loss of control was experienced in response to physical symptoms and over bearing concerns expressed by family. Patients took steps to accept their diagnosis, including learning to be grateful and developing willpower to face the illness. Cultural implications were noted with regards to Japanese identity and a tendency not to talk openly about feelings with the family. A loss of personal control was also a key feature of patient's experiences in a study by McVey et al (2001). Cancer patients undergoing surgery for ostomy formation were interviewed pre surgery (n=8), 2 weeks post surgery (n=7), and 3 months post surgery (n=4). A loss of personal control arose in response to the cancer diagnosis, physical symptoms and medical procedures. This loss of control was exacerbated by a lack of information, or misleading information. Patients adopted defensive strategies pre and post operatively; either by dismissing their fears or being overly optimistic.

Shaha and Cox (2003) interviewed seven patients newly diagnosed with colorectal cancer. Patients were interviewed weekly for a month, then twice monthly for two months, then monthly up to a year. Patients therefore potentially participated in 17 interviews, with an opportunity for additional interviews and telephone contact if they wished. One main category emerged from the data: "The Omnipresence of Cancer", with two sub categories: "Towards Authentic Being" and "Mapping Out the Future". The individual felt stigmatised by their illness and the diagnosis had an overwhelming impact upon their understanding of life. They experienced a loss of control and

uncertainty, and existence was transitory. Deciding to take control and return to a sense of normalcy caused a change in behaviour and outlook. Some chose to reject treatment, some chose to be comfortable in the time they had left. The patients considered the study as a forum for discussion and reflection upon their understanding and experiences. This is not surprising due to the variable interviewing schedule, which afforded the patient some control in determining the number and nature of contact. It could be argued that patients wishing to participate in frequent interviews perhaps had a stronger desire or need to unburden, and may have entered into a therapeutic relationship with the interview team. It could also be argued that regular and repeated discussions of feelings regarding a diagnosis of cancer could create a self-perpetuating omnipresence, potentially restricting an individual from 'moving on'.

Ramfelt et al (2002) interviewed 52 patients with colorectal cancer, at three time points over a one year period. The authors aimed to explore changes in emotional and interactional perspectives of illness following diagnosis. Analysis suggested that the body and body perception were fundamental to the patient's ways of finding meaning in illness as patients attempted to achieve emotional coherence. Patient's experiences had two dimensions which coexisted and overlapped, with no clear boundaries. One dimension was unified embodiment, referring to the meanings ascribed to the body and built upon past experiences and memories. Emotions were characterised by a united body-self, creating a sense of confidence and looking forward to a new future. The other dimension was dichotomised embodiment, characterised by the struggle with the violated body, loss of integrity and altered self values. The sample included those diagnosed with metastatic disease which may add additional burden to the emotional impact of diagnosis. A methodological limitation relates to data collection as participants' had to choose one of 8 predetermined categories of perceived meaning of an illness. Therefore, all

subsequent data collection and analysis aimed to refine a predetermined category which the authors fail to discuss as a potential source of bias.

Taylor et al (2010) undertook a prospective grounded theory study with 16 patients over twelve months following surgery for colorectal cancer. As a consequence of colorectal cancer and surgery, patients experienced a disconnection with their body and lost body control. The loss and unpredictability of normal body function had to be overcome through understanding changes within the body and discovering patterns of predictability. Recovery was determined by processes internal to the body, shaped by meanings attached to health, illness and the contextual situation. If a relationship with the body was not re-established then recovery could not progress. Recovery was therefore experienced as four conceptual stages: disembodiment; restoring embodiment; reclaiming control; and managing embodied control.

2.6.1 Summary of studies of patient experiences

Similarities can be seen across studies using interviews to explore patient's experiences. The cancer diagnosis and treatment causes a loss of control and creates a sense of uncertainty, particularly regarding the future. Studies suggest that in response to physical symptoms and functional difficulty, patients may withdraw from friends and society, leading to social isolation. However, the majority of studies have collected cross sectional data which fails to consider patient experiences over time. Notable exceptions to this are Taylor et al (2010), Ramfelt et al (2002) and Shaha and Cox (2003) who conducted longitudinal studies. To date, there has been less attention to the patient's experiences over time after they complete treatment.

2.7 *Illness experience*

Illness as experience has conceptually and theoretically evolved within the discipline of sociology. Texts and theories explore the diversity of everyday experiences, consider the meanings attached to illness and actions people take to manage, mitigate and adapt to illness (Bury 1991). Sociologists are concerned with social interaction and processes while theoretical propositions are made relating to concepts such as identity and self (Corbin 2003; Charmaz 1983). Theories aim to explain how people construct and represent themselves, and how this is influenced by illness (Corbin 2003; Corbin and Strauss 1987). This body of work has produced a relatively homogeneous set of concepts dealing with continuity and discontinuity along the life course, with an underlying theme relating to identity (Armstrong 2003). These texts offer conceptual vocabulary and theoretical considerations which may have applicability to patients who experience cancer as an acute illness episode through attention to social interaction and processes, the meaning of illness and the actions of the individual as they progress through recovery.

2.7.1 Biographical disruption

Bury (1982) proposes biographical disruption as a conceptual framework of continuity and discontinuity along the life course. Continuity of the life course is viewed as biographical time, where events are anchored in a context of the past, present and future (Corbin 2003). Time takes on a different dimension as a result of illness: "Illness intrudes into life, disrupting biographical time" (Corbin 2003:259). Bury (1982) interviewed thirty people with an emerging, and probable diagnosis of rheumatoid arthritis. His aim was to explore processes of recognition of illness, and changes in life situation as a consequence of the development of illness (Bury 1982). Bury (1982:169) suggests that illness is "that kind of experience where the structures

of everyday life and the forms of knowledge which underpin them are disrupted". He proposes that the development of chronic illness is most usefully regarded as a critical situation, which "involves a recognition of pain and suffering, possibly even death, which are normally only seen as distant possibilities or the plight of others" (Bury 1982:169). The individual has an expectation of a life they will live, and the experience of illness causes a shift from this perceived life biography, to one that is fundamentally abnormal and inwardly damaging.

Disruption has three aspects, the first being disruption of assumptions and behaviours. Illness causes failure of a trustworthy or taken for granted body, resulting in loss of function and reliability. This causes the individual to experience a re-awakening of the fallibility of their body, causing the normally absent body to be brought into consciousness (Leder 1990). Recognition of illness is complex when symptoms are often insidious and not recognised or attributed to a "common sense attitude" (Bury 1982). The second aspect of disruption occurs to normal explanatory systems, requiring a rethinking of biography and self concept. Uncertainty is encountered when the individual has to rethink their biography in response to illness, creating difficulty and unpredictability with determining outcomes. Medical knowledge provides an opportunity for the individual to conceptualise disease as separate from the self, and to adopt a "victim" stance where external forces are responsible for the individual's current predicament (Bury 1982). The final aspect of disruption relates to the individual's ability to mobilise resources in response to their illness. This includes the wider social networks and communities available to the individual (Bury 1982). Cultural aspects and associations of stigma may disrupt normal social networks, particularly if there is a sense of embarrassment associated with the illness (MacDonald 1998). Alongside the setting within which disruption occurs, the meaning of illness is brought into focus (Williams 2000a). Bury (1988) distinguishes

between meaning as consequence and meaning as significance. The consequences of illness relate to the effect of disruptive symptoms on everyday life, which requires a practical response from the individual including resources of time and energy required to manage the illness (Rosenfeld 2006; Williams 2000a). Meaning as significance relates to the symbolic significance of the illness, including the interactional dimension and impact upon the individual's personal, social and biographical world (Bury 1988; Rosenfeld 2006).

Bury's framework of biographical disruption (1982) has been used by Hubbard et al (2010), to explore the extent to which 18 people experienced colorectal cancer as biographically disruptive. Each participant was interviewed on three separate occasions over twelve months following diagnosis. The interviews were part of a larger study and used a pre determined interview guide informed by United Kingdom cancer care policy and advice from advisory groups. No information was provided regarding disease staging, and patients received multiple treatment modalities. The time intervals between interviews were not specified. Interview transcripts were compared to elicit descriptive themes, and then interpreted using a thematic framework drawn from Bury's concept of biographical disruption (1982) and Charmaz's concept of identity (1983). No outline of the descriptive themes or thematic framework is provided.

Whilst some individuals did experience biographical disruption, Hubbard et al (2010) argue that the universal application of the concept is not appropriate because cancer may assault the physical and emotional self, and daily lives and social activities may be disrupted, but self identity is not threatened. Individuals may continue to engage in biographical work as they have always done, not influenced by illness. However, the supporting data excerpts they offer are ambiguous, and open to multiple

interpretations. One man is no longer able to engage in physical activities and hobbies due to his illness, and comments "I'm not going anywhere". Within the context of the full quote, his comment could be simply interpreted as an inability to mobilise, or alternatively, could offer an insight into his view of a future where he is no longer able to pursue purposeful and pleasurable activities. Their analysis appears to place emphasis upon the disruptive elements of the framework with less consideration of meaning as significance.

Bury (1997) and Williams (2000a) highlight the need for ongoing theoretical and empirical development of biographical disruption. The idea that the level of disruption created by illness may be influenced by age and position on the life course has been considered by several studies. Sanders et al (2002) considered the meanings of symptoms within the context of cultural connotations of ageing. They conducted interviews with 27 older people with osteoarthritis, aged 51-91 years. Interviewees believed the development of osteoarthritis was bound up in their life history within a biography of hardship and hard work, where natural bodily degeneration was inevitable and to be expected. As a consequence, many did not seek treatment for their arthritis, even when consulting the doctor about other ailments. Participants were keen not to be seen as a burden within society where arthritis was viewed as a crippling illness of older age. Symptoms were disruptive to everyday life, but societal and personal negative images of disability led participants to downplay their symptoms.

Pound et al (1998) interviewed 40 working class people, ten months after experiencing a stroke. The elderly patients had a mean age of 71 years and accepted a stroke with pragmatism, normalising the stroke as a fundamental and inevitable part of life. In the same study and in contrast, two younger patients

emphasised the tragic and disruptive effect of stroke on their lives. Many of the elderly patients had "hard earned lives", involving physically demanding work, financial hardship, poor health and co-morbidities. Within the context of financial hardship and inadequate housing, they described the stroke as "not that bad". Faircloth et al (2004) also cite co-morbidity, previous illness experiences and age as mediating factors in the experience of stroke. Elderly veterans participated in several interviews over two years following discharge from hospital after a stroke. The majority previously had poor health and the sudden onset of stroke was an event which came and went with little influence on everyday life. Pound et al (1998) comment that there is an implicit assumption in the literature of chronic illness as biographical disruption, that illness affects lives which have been previously untouched by crises or struggles. Faircloth et al (2005) suggest that rather than simply accepting the notion of biographical disruption, listening to and analyzing how a person defines and interprets illness provides valuable insights. In an early paper from the same study, they suggest recovery is less about managing disruption and is more about *biographical flow* where the stroke is integrated into ongoing life (Faircloth et al 2004; added italics).

These three studies emphasise the importance of context to the illness experience, pre existing health and lifestyle, age and cultural connotations. Becker and Kaufman (1995) note differing cultural perspectives between elderly patient and physician frameworks of understanding with regard to stroke. Physicians viewed stroke from a medical perspective of location and degree of lesion, which lessened their expectations of successful rehabilitation. In contrast, patient's attitudes were founded on a belief of neurological recovery, promoted by personal effort at rehabilitation and mental attitude. Becker and Kaufman (1995) associate the beliefs of physicians with

a cultural attitude embedded in policy which limits the amount of therapy an older person can receive and where the old cannot recover or tolerate rehabilitation.

Societal views of illness have been discussed by Carricaburu and Pierret (1995). They interviewed HIV positive men who were infected either through gay sex or through medical treatment for haemophilia. Their HIV status led these men to reinterpret their individual and collective pasts which reinforced their identity as a homosexual, or a man with haemophilia which had existed prior to their HIV infection. The gay men drew upon their generational plight to establish recognition of homosexuality, whereas haemophilic men reinforced their previous biography with illness as a daily aspect of life. The interrelations between the individual's experience of infection, his life story and the history of his reference group illustrate the collective and cultural aspect of the illness experience (Carricaburu & Pierret 1995). Gay men experienced HIV as biographically disruptive whereas haemophiliacs experienced HIV as biographical reinforcement because they had already modified their lifestyle to accommodate illness. They were experienced in living with uncertainty and had given up risk activities such as extreme sports. Infection with HIV therefore led to reinforcing the measures already adopted and confirmed the fatality of being haemophilic (Carricaburu & Pierret 1995). These studies promote the importance of locating the illness experience within a 'collective' context which extends beyond the immediacy of the individual and their biography (Lawton 2003).

2.7.2 Illness and identity

Studies have also explored the impact of illness upon personal identity. The tradition of symbolic interactionism (Blumer 1969) conceives of identity as a means of defining and differentiating the self from others. This involves taking account of people's

preferred identities, and identity goals they desire, hope and plan for the future (Charmaz 1995). Identity is the parts of the self and meanings attached by persons to the multiple roles they play in contemporary society (Stryker & Burke 2000). The individual derives a sense of identity from their personal and internal recognition systems, and also from the behaviours and attitudes of those around them (Flanagan & Holmes 2000; Gillies & Johnston 2004). So whilst personal identity is at the core of the individual and experienced as unique, identity is subject to cultural and social patterning (Hitlin 2003). Identity has some aspects which remain stable over time (Bozinovski 1998), and other aspects which are transformed through daily interactions within the lived world (Williams and Bendelow 1998). Illness may present a crisis which creates a loss of self because former actions, lives and selves are now precluded by illness (Charmaz 1983). Charmaz (1983) conducted interviews with 57 people with a variety of chronic diseases, all severely disabled and/ or housebound. Interviewees were aged 20 to 86 years, with a majority being relatively young, aged 40-60 years. Charmaz describes chronic illness as not simply about physical suffering but also the challenges to personal identity. Charmaz conceptualised interviewees experiences as "loss of self" where assault to personal identity raised doubts of self-worth. People experienced "a crumbling away of their former self-images without simultaneous development of equally valued new ones" (Charmaz 1983:168). Identity was threatened by the loss of valued attributes, physical functions, social roles and personal pursuits (Charmaz 1994; Charmaz 1995). The effects of illness for a relatively younger age group were reflected in an inability to work. Multiple losses created a multi-faceted experience, fostering an all consuming retreat into illness, restricted lives, discreditation and social isolation. Different aspects of the illness experience reinforced and amplify one another, potentially creating irreversible consequences (Lawton 2003).

Irreversibility is alluded to by Mathieson and Stam (1995) who suggest identity undergoes a permanent transformation in response to a diagnosis of cancer. They employed theoretical sampling and conducted semi-structured interviews with 37 individuals, ranging from less than 6 months to over 60 months since diagnosis. Using inductive analysis and grounded theory, "identity work" emerged from the data where individuals describe three phases: identity threat; renegotiating identity; and biographical work. In the early phase of illness, identity is threatened by the cancer diagnosis as the individual experiences "disrupted feelings of fit" arising from an awareness of former healthy lives and lives now revised by illness. The individual begins to feel like a different person. Renegotiating identity involves a response to the diagnosis and acknowledgement of a permanent transformation. The stigma of cancer requires patients to renegotiate their identity by monitoring their relationships, causing social withdrawal and for some, self imposed social isolation. Biographical work is the third phase and is a life long activity, fundamental to a sense of identity. Biographical work requires a 'social space' where the individual revises their self and biography, and where illness or health takes precedence in the foreground.

The concept of the duality of health and illness is developed further in the shifting perspectives model of chronic illness (Paterson 2001; Thorne and Paterson 1998). A collaborative team of seven investigators conducted a metastudy of 292 qualitative research studies about the experiences of adults with chronic illness. They determined that sociological research was evolving from a focus on loss and burden, towards images of health within illness (Thorne and Paterson 1998). The shifting perspectives model conceptualises living with chronic illness as a continuously fluctuating process in which illness or wellness is prominent in the foreground (Paterson 2001). The model directs particular attention to changes in behaviour and explanations adopted over time by the individual with chronic illness.

The evolving perspective of health and illness with changes in behaviour have also been noted by Godfrey and Townsend (2008). They conducted qualitative interviews with 64 older people and 21 informal carers. Prior circumstances (social and functional ability) and type of illness (crises, deterioration in health, acute exacerbation of chronic illness and planned procedures) were important factors in the types of recovery trajectory experienced. Four trajectories were created from the data, including the trajectory of adjusting to discontinuity and re-establishing continuity. For patients with cancer, the onset of illness created an overwhelming sense of disruption and the meaning of recovery was tainted by uncertainty. Success in redeveloping identity and recovery was informed by regaining a sense of continuity within a life with pleasure or symbolic significance. Meaning of recovery changed over time as the individual had to adjust and reappraise options available to them. The experience and process of recovery was partly determined by resources available to individual, including internal resources, relational and practical help.

2.8 *Definition of recovery and experience*

The literature review has shown variation in how studies have considered recovery as a concept. Some have emphasised a biomedical view of functional recovery and quality of life as sequelae of treatment. These studies have adopted a view of recovery as something objective and measurable. Some studies have taken a broader approach to exploring patient experiences.

The Oxford Dictionary (2010 online) defines recovery as "1) a return to a normal state of health, mind or strength, 2) the action or process of regaining possession or control of something lost or stolen". Recovery is therefore seen as a process of restoring a

previously held state of health, with an implicit assumption that a full return is possible. Entering search terms of "recovery colorectal cancer" into an internet search engine retrieve references regarding the medical treatment of colorectal cancer, with a particular emphasis upon pharmacological treatment or surgical techniques. This confirms a positivist approach where recovery is perceived as an observable and measurable outcome.

In contrast, the concept of experience is more broadly defined in the dictionary as "1) practical contact with and observation of facts or events, 2) knowledge of skills acquired by a period of practical experience, 3) an event or occurrence which leaves an impression on someone" (Oxford Dictionaries 2010 online). These definitions include a subjective component, where experience provides an opportunity for evolution or change. Jacobson and Greenley (2001) describe recovery as a combination of internal conditions (attitudes, experiences and processes of change within individuals) and external conditions (the circumstances, events, policies and practices that may facilitate recovery). This broader definition includes the wider context of both subjective and emotive feelings.

2.9 *Summary of chapter*

This chapter has reviewed the literature regarding recovery following treatment for colorectal cancer. Some studies have used a biomedical framework to consider quality of life measures as indicators of sequelae of treatment. Symptoms of pain, insomnia and fatigue are common and may persist for many months following surgery. Studies of patient experiences have suggested the cancer diagnosis and treatment cause a loss of control and create a sense of uncertainty. In response to physical symptoms, the individual may withdraw from their social group, creating

social isolation. Little research has adopted a longitudinal design to consider the individual over time as they experience recovery. Less attention has been given to the subjective and emotive impact of colorectal cancer upon the individual's experience of recovery.

CHAPTER 3: METHODOLOGY AND METHODS

3.1 Introduction

This chapter discusses the methodological considerations when undertaking this study. Firstly, the context for the study is established by briefly reiterating the background for choice of topic area. Research paradigms are described and how consideration of these influenced the choice of methodology: grounded theory. The philosophical and theoretical underpinnings for grounded theory will be presented. The methods of the study are then discussed, including choice of sample, data collection and data analysis. Reference will be made to issues of methodological rigour and the role of the researcher. Finally, the ethical issues relating to this study will be addressed.

3.2 Context

As outlined in the introduction, the original research area arose from clinical observations regarding the individual's experiences following discharge from hospital. The service development project suggested a disparity between individual's experiences and statements of policy with regards to information acquisition. To develop this study, it was necessary to consider the paradigm and associated epistemological and methodological assumptions which guide the research process (Annells 1996). Methodology can be simply viewed as the "overall strategy for resolving the complete set of choices or options available" (Guba & Lincoln 1989:183). The methodology chosen must fit the purpose and nature of the area under investigation (Morse 1991). Consideration of these issues was required to determine the appropriate methodology for this study.

3.3 Research paradigms

A paradigm is defined as a "basic set of beliefs that guides action" (Denzin & Lincoln 2000:19). Social research commonly discusses two main paradigms: directed by either positivist; or by naturalist or interpretive beliefs (Hammersley 1992). The two paradigms make different assumptions based upon the ontological and epistemological position. Ontology is the branch of metaphysics that deals with the nature of being, the social world and the place of people within that world. Epistemology is the branch of philosophy concerned with origins, nature, methods and limits of human knowledge. Lincoln and Guba (1985) describe a number of "axioms" based on an understanding of epistemological differences between positivist and naturalist paradigms (table 3). Some authors argue that paradigms cannot be viewed simply as two opposing ends of a spectrum (Guba 1983, Hammersley 1992). Hammersley expands to suggest that many components actually represent a range of positions located in more than one dimension and therefore, methodology choices should depend upon the purpose and circumstances of the research.

3.3.1 Positivism

The positivist paradigm is based on realist ontology which assumes that reality is ordered, can be observed and measured. It is rooted in natural science and stresses the importance of objectivity. The ontological position assumes that objective reality exists and is driven by scientific law. Epistemologically, the researcher or observer is seen as independent from the object or subject of study, thereby remaining distinct and separate (Guba & Lincoln 1989; Johnson & Onwuegbuzie 2004). Studies in this paradigm adopt quantitative methods and focus on rigor, objectivity and control.

Table 3: Contrasting positivist and naturalist axioms

(application to this study in **bold**)

Axiom	Positivist paradigm	Naturalistic paradigm
The nature of reality	Reality is single, tangible, and fragmentable.	Realities are multiple, constructed and holistic. (multiple realities exist for the individual: their individualism; their social and home environment; health services)
The relationship of researcher to the researched	Researcher and researched are independent, a dualism.	Researcher and researched are interactive and inseparable. (longitudinal data collection, researcher "lives alongside" whilst exploring the individual's recovery)
The possibility of generalisation	Time and context free generalisations are possible.	Only time and context bound working hypotheses are possible. (the recovery experience will evolve as the individual moves through time and place; recovery is not static)
The possibility of causal linkages	There are real causes, temporally precedent to, or simultaneous with their effects.	All entities are in a state of mutual simultaneous shaping so that it is impossible to distinguish causes from effects. (multiple influences may cause multiple changes in recovery; prediction is not possible)
The role of values	Inquiry is value free.	Inquiry is value bound. (values: researcher is situated within naturalist paradigm; directed by grounded theory as inductive process to seek meaningful exploration of experiences of individual)

(Adapted from Lincoln & Guba 1985:37)

Quantitative methods aim to test hypotheses, validate or repute theory and establish facts and causal relationships. Research proposals will outline all phases of the study and attempt to predetermine all possible problems (Denzin & Lincoln 1998). Terminology used includes reliability, internal and external validity, and objectivity (Denzin & Lincoln 2000). Examples of health care studies within this paradigm evaluate the patient experience by measuring symptoms or responses to medications or treatments. Limitations of quantitative research are often linked to the relatively narrow perspective on the phenomenon being studied and in particular the lack of a holistic view surrounding data collection and interpretation.

3.3.2 Naturalism

In contrast, the naturalist or interpretive paradigm draws on a range of philosophical and sociological ideas. This paradigm is based on multiple truths and realities (Guba 1990), and assumes a relativist ontology (Denzin 2000). In this paradigm, social context and processes are acknowledged for their impact on an individual's beliefs and experiences. Proponents of this view believe that time and context free generalisations are not possible or desirable and that research is value-bound (Guba 1990). The research follows a path of discovery using a variety of qualitative methods (Denzin & Lincoln 1998). The researcher and the researched are seen as interdependent and that both influence the other within the research process. The values and beliefs of the researcher influence how they explore and interpret the views and perspectives of the participant (Smith 1983). The researcher draws on their own experiences to think reflectively, biographically and historically (Denzin & Lincoln 1998). Researchers within this paradigm commonly adopt qualitative methods to gain understanding and insight through discovering the meanings attached to a given phenomena. Qualitative researchers study phenomena in their

natural settings, using multiple methods based on an interpretive, naturalistic approach to the topic of inquiry. They aim to make sense of, or interpret phenomena in terms of the meanings people bring to them (Denzin & Lincoln 1998). Qualitative methods can be valuable to study a phenomenon about which little is known and to gain new insight or understanding about well known areas (Strauss & Corbin 1990). Qualitative methods emphasise the value of individual experiences and views (Hewitt-Taylor 2001), with the explicit goal of description of the data (Glaser & Holton 2004). Qualitative research does not aim to be objective, rather it recognises the context and the impact of the surroundings and situations upon the phenomena (Barbour 2001). Interpretive methodologies focus primarily on understanding and accounting for the meaning of human experiences and actions (Fossey 2002). Qualitative researchers collect data from people, often in their natural environments. They explore how cultural, social and other factors influence the experiences and behaviours. This is achieved through attention to narratives and language, to explore themes which emerge from the data (Coyle & Tickoo 2007). Confusion may arise when researcher's use the terms qualitative methods and naturalistic methodology interchangeably. What is of importance is that the underlying justification for a study should be based upon an epistemological stance and a belief in how knowledge is gained, rather than simply how the data is collected and analysed. Studies which use qualitative methods but are designed in terms of positivist assumptions remain positivist studies (Sperber 1996). The stance and beliefs adopted by the researcher determine the methodology (Smith 1983).

Guba (1990) postulates that a paradigm can be characterised by the way their proponents respond to the following three questions: 1) the ontological question: what is the nature of knowledge or reality, and what can be known about it? 2) the epistemological question: what is the relation between the knower and what can be

known? 3) the methodological question: how can the inquirer go about finding out what they want to know? In response to these questions in this study, adopting a naturalist approach enables a broader conceptual consideration of the social and cultural meanings which may influence the individual's experiences of recovery. The individual acts and interacts within their personal environment, and in relation to the actions of others, including health service providers. The researcher enters the individual's environment through the data collection process and aims to explore this world through the participant's descriptions. The interpretive nature of the naturalist paradigm allows theoretical development within a relatively unexplored topic area and seeks to propose relationships among concepts which may be used to guide future actions (Strauss & Corbin 1990).

3.4 *Early literature review*

Literature reviews conducted for the formative assignments (see part II) have provided the context for the study and served to refine the focus of study. To summarise, key findings from these early literature reviews suggest that Government policy emphasises autonomy and individual responsibility with regards to health. Information provision is seen as central to promoting the individual's ability to be autonomous and self determining. Colorectal cancer is a significant disease burden worldwide and yet relatively little research has been conducted within this patient group. Within the colorectal cancer domain, much of the research has adopted a biomedical framework and measured quality of life as an indicator of sequelae of surgical treatment. Less attention has been given to the longitudinal nature of recovery and the subjective, emotional impact of colorectal cancer upon the individual's experiences. The topic area is relatively unexplored and theoretically undeveloped and therefore an inductive approach is appropriate. In this paradigm,

the researcher has no preconceived hypotheses, remains open minded, flexible and allows the theory to emerge from the data (Glaser & Strauss 1967; Strauss & Corbin 1990).

3.5 *Grounded theory*

Grounded theory as a methodology was first described by Glaser and Strauss (1967). These two authors represented two differing positions in sociological research. Barney Glaser initially trained in positivism and quantitative social research methods, whilst Anselm Strauss was educated in pragmatism and field research (Charmaz 2006). They collaborated in the 1960's, to study dying in hospitals. They acknowledged that neither of their respective traditions had successfully bridged the gap between theory and empirical research. In response they developed grounded theory, with an additional purpose of answering criticisms of positivist researchers that qualitative research was unscientific because it lacked rigour (Glaser & Strauss 1967). Glaser's influence on the development of grounded theory can be seen through the emphasis on logic and a systematic approach, rigorous coding methods and emphasis on emergent discoveries. Strauss' contribution focused on human beings as active agents, the subjective and social meanings within language, the view that process and not structure is fundamental to human existence (Charmaz 2006). Together, they developed grounded theory as an alternative to the positivist research approach which was popular in sociology at the time (Jeon 2004).

Grounded theory is a research method which "uses a systematic set of procedures to develop an inductively derived grounded theory about a phenomenon" (Strauss & Corbin 1990:24). Grounded theory focuses on the everyday experiences of individuals in their social world, as they construct and reconstruct reality through

ongoing interaction. The focus is upon the participants' perspective, using naturally occurring data sources and comparison groups which are theoretically sampled to inform the developing theory (Glaser & Strauss 1967). Glaser and Strauss (1967) state the defining components include: simultaneous involvement in data collection and analysis; constructing analytic codes and categories from the data; using the constant comparative method; advancing theory development during each step of data collection and analysis; memo-writing to elaborate categories; specifying properties and defining relationships; sampling aimed toward theory construction and conducting the literature review after developing the analysis. The method is highly structured but flexible, with explicit procedures for data analysis. Interestingly, Glaser and Strauss provide limited direction or instruction for methods of data collection (Charmaz 2000), but whichever techniques are employed, they must collect rich and deep data. The basic strategies within grounded theory include theoretical sampling, systematic coding, conceptual density, variation and integration (Denzin & Lincoln 1998). The "pacing of these procedures is, at once, simultaneous, sequential, subsequent, scheduled and serendipitous, forming an integrated methodological whole that enables the emergence of conceptual theory" (Glaser & Holton 2004, online). Grounded theorists are interested in the patterns in action and interaction; and discovering process (Strauss & Corbin 1998).

3.5.1 Grounded theory and theories

The objective of grounded theory is the development of theory which explains the basic patterns common in everyday social life (Chenitz & Swanson 1986). This emphasis on theory development is what separates grounded theory from other qualitative research approaches (Strauss & Corbin 1998). A theory is a set of relationships proposed between concepts and sets of concepts (Strauss & Corbin

1998). Rather than aiming to verify existing theory, grounded theory aims to build theory which is 'grounded'; purposefully and systematically generated from the data (Glaser & Strauss 1967; Annells 1996). The emphasis is on "*theory as process*; that is, theory as an ever-developing entity, not as a perfected product." (Glaser & Strauss 1967:32, *original emphasis*). They contend that a good theory should explain, predict, and be useful. The functions of theory are these: "... (1) to enable prediction and explanation of behavior; (2) to be useful in theoretical advance; (3) to be useful in practical applications - prediction and explanation should be able to give the practitioner understanding and some control of situations; (4) to provide a perspective on behaviour - a stance to be taken toward data; and (5) to guide and provide a style for research on particular areas of behaviour" (1967:3). They argue that theory should be inductively generated through the systematic analysis of empirical data. In their view, the key to successful theory generation is the use of the general comparative method. One must systematically compare similar, and sometimes dissimilar, events or situations. Only in this way can theory be progressively built up so that it is generally applicable to the social behavior under study. Grounded theory can generate two basic types of theory: substantive or formal. The researcher must be clear as to which level they are focused on because the strategies vary for arriving at each one (Glaser & Strauss 1967). Formal theories are quite general and address a conceptual level of inquiry (Glaser & Strauss 1967), such as formal organisation or socialisation. Substantive theories are the more common type and focus on an empirical area of sociological inquiry (McCann & Clark 2003). Grounded theory, adopting a symbolic interactionism underpinning, aims to generalise beyond the individual experience but retain a mid-range theoretical perspective on local systems and context (Reeves et al 2008). These mid-range theories consider specific phenomena and involve a small number of concepts relating to a restricted range of contexts (Reeves et al 2008). The aim to develop a substantive theory relating to the

experience or recovery was deemed important as the early literature review had indicated that relatively little theoretical development had occurred.

3.5.2 Symbolic interactionism

Grounded theory as developed by Glaser and Strauss, has adopted symbolic interactionism as its theoretical underpinning. Early foundational work to develop the symbolic interactionism perspective was undertaken by George Mead (Benzies & Allen 2001). Mead acknowledged the contribution of social interaction and situation on the individual in developing a sense of self (Strauss & Corbin 1990; Chenitz & Swanson 1986). His student, Herbert Blumer is credited with the further development and refinement of the theory, and adopting the term 'symbolic interactionism'. Symbolic interactionism seeks to explain human behaviour in terms of meanings. It is underpinned by three basic assumptions:

- People, individually and collectively, act towards things according to the meanings they ascribe to them.
- These meanings are derived from the process of social interaction.
- Meanings constantly change and are modified according to the interpretive process between a person and the things they encounter (Blumer 1969).

Symbolic interactionism is a theory about human behaviour, the study of human conduct and the meaning of events (Chenitz & Swanson 1986). Interactionism focuses on exploring collective (group) behaviours and perceptions (Reeves et al 2008). The theory assumes society, reality and self are constructed through interaction (Charmaz 2006). Symbolic interactionists have a non-deterministic view of the individual and believe that an individual has freedom of choice in their behaviour, although their choice may be influenced or constrained by societal and cultural norms. The theory is concerned with the study of the inner or experiential aspects of

human behaviour, that is, how people define events or reality and how they act in relation to their beliefs. People create "symbols" from their experiences and through these symbols they define themselves and their situation (Szostak 2003). A core tenet of symbolic interactionism is that the individual and the context in which that individual exists are inseparable. Human behaviour has to be examined in interaction and within natural settings. Individuals are seen to be purposive in their actions in response to environmental cues, objects and others, and the perceived meanings attached to these (Goulding 1999). Symbolic interactionism suggests that one of the main tasks for the individual in interaction is to establish a definition of the situation (Cast 2003). Individuals control this definition by:

- Behaving in ways consistent with their identity
- Influencing the behaviour of others
- Resisting identities that others seek to impose on them.

Central to symbolic interactionism is the importance of the constantly evolving nature of experience: the concept of change in terms of perceptions, interpretation and meaning (Strauss & Corbin 1990). Symbolic interactionism takes the *interaction* as the unit of analysis, not the individual (Hollander & Howard 2000, *added emphasis*).

3.5.3 Diversification of grounded theory

The initial work published by Glaser and Strauss (1967) is now often coined 'Classic Grounded Theory'. Classic grounded theory was guided by critical realist ontology and a postpositivist paradigm (McCann & Clark 2003). Subsequently, both authors continued to refine and develop their work, albeit in differing directions (Charmaz 2000). Whilst both methods share common characteristics, significant differences now exist in the underlying philosophical assumptions (McCann & Clark 2003) (see table 4). Glaser maintained his objective stance and a focus upon theory generation

(Glaser 1978; Glaser 1992), whilst Strauss and his co-author Corbin developed a greater emphasis on theory verification (Strauss & Corbin 1990; Strauss & Corbin 1998). Annells suggests these developments indicate that grounded theory is maturing and branching, and that one method does not have superiority over the other (Annells 1997a). Where differences exist within the common characteristics, these often relate to the degree to which the element is adopted (McCann & Clark 2003). The divergence in methodology advocated by the two originators of grounded theory can present difficulties for the novice researcher when attempting to choose an appropriate methodology (Charmaz 2006). Charmaz (2006) contends that basic grounded theory guidelines can be used, adopted and adapted to suit the nature and purpose of the research study (Charmaz 2006). Indeed, this is advocated as a positive and necessary development which emphasizes "flexible guidelines, not methodological rules, recipes, and requirements" (Charmaz 2006:9). Grounded theory is still a relatively young research tradition and therefore should be subject to ongoing development, transformation and critique (Woods 2003).

Extensive reading of the classic grounded theory text (Glaser & Corbin 1967), and later publications by Strauss and Corbin, did initially create difficulties with regards to choosing a methodology for this study. Annells (1997a) proposes that both paradigm and methodological issues have to be considered, alongside practical issues. Strauss and Corbin's writings (1990; 1998) were clear and easy to follow which was a strong attraction to a novice grounded theorist. Strauss and Corbin focus upon a phenomenon and a pre identified problem, which seemed to fit with the concept of recovery as a process. The perspective and interactions of the researcher are deemed integral. Strauss and Corbin (1990) comment that the professional and personal background of the researcher will influence analysis and enhance

Table 4: Epistemological and methodological differences between Glaser's and Strauss and Corbin's approaches to grounded theory
(application to this study in **bold**)

	Glaser	Strauss & Corbin
Epistemology	Critical realist ontology and post-positivist paradigm. More positivistic	Social constructivist and poststructuralist or postmodern paradigm. Less positivistic.
Researcher's role	Independent.	Dialectic and active. (personal and professional background of researcher is positive force for analysis process)
Theory	Emphasis on theory generation.	Emphasis on verification and validation of theory and hypotheses. (theory is linked to local and constructed reality)
Focus in the field	Main emphasis on symbols, interactions and context. Emphasis on socially constructed world of participants (micro).	Emphasis on structural, contextual, symbolic and interactional influences. Emphasis on describing cultural scene (macro) and socially constructed world of participants (micro). (culture of secondary care/ primary care; symbolism of cancer; recovery with limited interaction from health professionals)
Literature review	Main review to support emerging theory.	Preliminary review to enhance theoretical sensitivity. Main review to support emerging theory.
Research problem	Emerges in study.	Personal experience; literature; emerges in study. (observations in clinical practice; policy review; service development project)
Data collection and analysis	Principles and practices of qualitative research. Guided by participants and socially constructed reality.	Rules and procedures. Paradigm Model to provide structure.
Evaluation	Fit, work, relevance, and modifiability.	Deference to canons of qualitative research outlined by other qualitative researchers. (reflexivity)

(from McCann & Clark 2003)

theoretical sensitivity. Annells (1997b) comments that Strauss and Corbin's techniques therefore encourage the use of personal experience and acquired knowledge to advantage. Again, this is deemed to have congruence with the thesis representing the final phase of the DClinPrac programme, which aims to marry critical thinking, clinical expertise and advanced research skills.

3.6 *Rationale for choice*

Symbolic interactionism is an appropriate theory to underpin nursing research where the emphasis is upon the natural world of human behaviour. Symbolic interactionism facilitates the exploration of how patients interpret and interact within their world. This is achieved by devoting attention to both the local and the larger social structural contexts (Hollander & Howard 2000). Symbolic interactionism proposes that the researcher must actively interact with the participant of the research study and see things from their point of view, and in their natural context (Jeon 2004). A common criticism of symbolic interactionism is that it fails to adequately address issues of social structure and power. Furthermore, material and institutional factors which underlie and influence the interaction are not fully recognised or explored (Hollander & Howard 2000). I was curious to understand whether issues of power and social health structures had an impact on patient's experiences following a move from secondary health to their 'normal' home environment. Grounded theory, incorporating a symbolic interactionism perspective, is an interpretive approach which can generate research based knowledge about behaviour patterns in particular contexts (Chenitz 1986). Grounded theory focuses on the individual's view of 'self' and how their interpretation of meaning influences their behaviour. I was interested in how a patient's interpretation of meaning would be influenced by their health and contact with health services. Grounded theory would facilitate the exploration of

more than simply the physical recovery for patients after colorectal surgery. Finally, grounded theory also encourages the researcher to be 'context aware', not only of the immediate environment but also other potential factors which may impact on the phenomena. The context and social nature of modern health care is often focused upon new technology; biomechanical developments in treatment and patient management, including remote self-management by the patient. Grounded theory and symbolic interactionism require consideration of this wider social context. As a result of this wider reading, I finally settled on an approach to use for this project: that proposed by Strauss and Corbin (1998). I felt it was important to identify both structural and contextual influences as I wanted to explore how patients responded to the discontinuation of regular contact with health care providers.

3.7 *Methods*

The following section describes the aim of the study, and the procedures of the research process including determining the sample, data collection and analysis.

3.7.1 Aim of the study

The aim of this study is to adopt grounded theory to provide a detailed description and theoretical analysis of the individual's experiences after completion of surgery for colorectal cancer.

Research questions:

What is the process of recovery when the individual has experienced cancer as an acute illness, with rapid diagnosis and treatment, and a short hospital admission?

What is the experience of recovery when the individual has limited contact with health professionals after completion of treatment?

What are the issues with regard to health information provision for this group of individuals?

3.7.2 Literature review

One of the fundamental debates within grounded theory relates to the literature review. An exploratory review of the literature can be useful prior to finalising the general focus and specific method of the study (McGhee et al 2007). Strauss and Corbin recommend an early literature review to enhance the theoretical sensitivity of the researcher (Strauss & Corbin 1998). They also believe the literature can be a useful analytical tool as it can foster conceptualization (Strauss & Corbin 1998). Strauss and Corbin (1990) propose reviewing the literature early on for several reasons:

- It stimulates theoretical sensitivity.
- It provides a secondary source of data.
- It stimulates questions.
- It directs theoretical sampling.
- It provides supplementary validity.

An early literature review was useful to provide focus for the study and to ensure issues pertinent to the topic area had been understood. The literature review highlighted where areas of conceptual and theoretical development were required. Glaser is emphatic that the literature review must not be undertaken until the core category has been identified (Glaser 1992). Extensive reading in the substantive

area can result in the premature imposition of existing theories on the collection and analysis of data (Glaser & Holton 2004). On a practical level, Glaser suggests that a literature review may also prove to be an early 'red herring' in that the topic reviewed may well become redundant within the final grounded theory (Glaser & Holton 2004). Strauss and Corbin partly agree with this as they comment it is impossible to know beforehand what the significant issues will be and what theoretical concepts will emerge (Strauss & Corbin 1998). However both authors concur that sources discovered from the literature must be used to enhance, rather than constrain the theory development (Strauss & Corbin 1998; Glaser 1992). Using the literature to challenge the emerging theory can enhance the credibility of the theory, whilst simultaneously integrating the theory into existing bodies of knowledge (Heath 2006).

3.7.3 Theoretical sampling

A key feature of grounded theory is the use of theoretical sampling. Sampling is flexible and responsive, guided by the analysis and therefore closely linked to theoretical sensitivity (Strauss & Corbin 1990). Theoretical sampling is defined as "the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyses his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges" (Glaser & Strauss 1967:45). The initial sample is chosen to examine the phenomena where it is found (Chenitz & Swanson 1986) and is based upon the general subject or problem area (Glaser & Strauss 1967). This subject area of enquiry is termed the 'substantive area' in grounded theory (Urquhart et al 2010). At this stage, the researcher has an idea of where to sample, but not necessarily what to sample for or where it will lead (Coyne 1997). During initial sampling, the researcher is interested in generating as

many categories as possible and therefore must draw a sample from a wide range of relevant areas. As data analysis and open coding begin, subsequent samples are determined by the emerging theory (Goulding 1999). The aim of sampling here is to uncover potentially relevant categories, along with their properties and dimensions (Strauss & Corbin 1990). As concepts and ideas are developed from the analysis, the researcher will seek the sample from a variety of sources to further strengthen and examine the emerging concepts, conditions, context, action/ interaction, consequences, and theory. Sampling now "...focuses on *uncovering and validating those relationships*" (Strauss & Corbin 1990:185, *original emphasis*). The final phase of sampling is deliberate and occurs during selective coding when integrating the categories to validate the categories and form the theory. Theoretical saturation is said to be reached when no new insights emerge from the data relating to the theory and its categories (Glaser & Strauss 1967; Strauss & Corbin 1998).

Whilst mindful of the requirements of theoretical sampling, the sampling strategy has to conform to the requirement of the Local Research Ethics Committee. Ethics committees require details of the sample, including numbers and where recruitment will occur. The study was conducted in a cancer centre, attached to a district general hospital in South East England. Approval was granted by the Local Research Ethics Committee (Appendix C). The initial sample was derived from the caseload of two colorectal surgeons. Eligible participants were identified during the weekly colorectal multidisciplinary team meeting between December 2007 and July 2009. Eligibility criteria included those who had surgery for a tumour of the sigmoid bowel and either: histology results indicated adjuvant treatment was not required or the participant refused adjuvant treatment. Individuals with rectal cancer who had received pre operative radiotherapy/ chemotherapy and then surgery were also eligible (box 1).

Inclusion criteria:

1. Patients who had completed surgery for tumour of the sigmoid bowel and required no further adjuvant therapy.
2. Patients who had completed pre-operative radiotherapy and/ or chemotherapy, followed by surgery for tumour of the rectum and required no further adjuvant therapy.

Exclusion criteria:

1. Patients who required adjuvant therapy for their disease.
2. Patients who were deemed to be too psychologically or physically unwell (by the consultant, colorectal CNS or researcher) to either provide informed consent or participate in an interview.
3. Patients who were not conversant in English and therefore unable to provide informed consent.

Box 1: Inclusion and exclusion criteria

The aim was to identify participants who would have no contact with the hospital professional outside of routine outpatient follow up clinics unless initiating contact themselves. Following surgery, the individual was required to attend outpatients approximately ten days later to receive their histological reporting. At the end of their appointment the CNS provided a brief summary of the study and an information sheet (Appendix D). If they were willing, the CNS passed their name and contact number to the researcher, who then contacted them by telephone within five days (see figure 1).

As data analysis progressed, theoretical sampling was employed to further examine and strengthen the emerging concepts. When theoretical saturation of concepts and categories around diagnosis and initial treatment was achieved, two participants were purposefully recruited three months following treatment to refine categories surrounding the latter stages of recovery. When no new concepts or categories were emerging from the data, theoretical saturation had been achieved and recruitment

stopped. Glaser and Strauss (1967) highlight that it is not the number of cases which is crucial; rather it is the generation of categories and their properties. The final sample included 12 participants.

Figure 1: flow chart of recruitment process

3.7.4 Ethics

3.7.4.1 Research methodology

To adhere to ethical principles, the design and conduct of a research study must be rigorous and scientifically sound. There is broad agreement that an outline of the trustworthiness of the data and analysis is essential (Connelly & Yoder 2000), although as highlighted in chapter 3, the criteria to address trustworthiness is subject to debate. Spencer et al (2004) advocate four guiding principles for ensuring quality in qualitative studies, namely that research studies should: contribute to advancing knowledge or understanding about a topic or area; adopt a research strategy to answer the question posed; demonstrate rigour through transparency of process and results; provide credible results.

The methodological rigour of this study was monitored and ensured throughout all stages: through regular supervision; wide reading of the methodology literature; regular documentation of all decisions and processes undertaken; submission to LREC, University Ethics, and the local Research and Development Department. As recommended by Lincoln and Guba (1985) I kept a reflexive journal throughout to illustrate the process and decisions I made. I also had regular contact with the Colorectal CNS as a form of peer review and for clarification of any clinical issues arising from my data analysis.

3.7.4.2 Consent

Ethical processes within the study were concerned with ensuring voluntary consent. All potential participants were approached by the CNS who provided an introductory letter and information sheet regarding the study. If the participant expressed a willingness to participate, their contact details were passed to the researcher. This

ensured all potential participants had the right to refuse to participate without the researcher having access to their personal details. The researcher initiated telephone contact with individual's who had expressed willingness to participate. The telephone contact provided an explanation of the study and allowed the individual opportunity to ask questions. The right to refuse to participate; to withdraw at any time; or to omit or remove anything the individual said from the data was reiterated in the information sheet; during the first telephone contact with the researcher and at the beginning of the first interview. These safeguards ensured all participants were able to exert their right to refuse or withdraw at any time. During the first telephone call, verbal consent was confirmed to record the participant's comments in field notes, which were subsequently incorporated into the first interview. At the beginning of the first face to face contact, all participants signed a written consent form (Appendix E). A written consent form was also completed for any spouse who was present during the interview. The consent forms were kept in a locked filing cabinet by the researcher. Each participant was assigned a unique identification number to assure anonymity. Only one participant refused to participate, stating her preoccupation with her underlying health issues as demanding of her time. When the study was amended to include longitudinal data collection, process consent was adopted. Munhall (1991; 2007) discusses how qualitative research is an ongoing, dynamic and changing process and therefore consent has to be seen as a process, rather than a singular event. Process consent is an ongoing consensual process involving the researcher and participant in mutual decision making, and leads to mutual participation and mutual affirmation between participant and researcher (Usher & Arthur 1998). I re-advised the participant at the beginning of every subsequent meeting, of their rights to withdraw or remove any data, at any time, if they so wished.

3.7.4.3 Minimising harm

All participants were allocated a study number to ensure their details and data remained anonymous. Participating in the interviews was not felt to be burdensome, but I was mindful to not overtire the participants. At all times I used my nursing skills to monitor and ensure the participants' were physically and emotionally able and willing to continue. On one occasion a participant did become distressed during the interview so a short break was taken to allow them time to recompose themselves. They then expressed a desire to continue with the interview. In several interviews, participants' would ask me specific questions about their health; their recovery; and other aspects of their wellbeing. If I was able to answer the question and it did not impede the nature of the interview, I would answer to the best of my ability. In situations where I felt I would fundamentally change the nature of the interview I advised the participant that I would prefer to revisit that question at the end of the interview when I could provide full and undivided attention. In certain situations, particularly regarding treatment and physical recovery questions, I would advise them to contact their GP or the CNS as I was not qualified to answer.

3.8 *Data collection*

3.8.1 Demographic data

A demographic form was completed for every participant to record their coding number, age, gender, diagnosis, marital status, race/ ethnic identity, socio-economic status, education, occupation and religion (Appendix F). This data was deemed important to provide contextual information for the study (Charmaz 2006) and because attention to macro factors such as societal and cultural position is

fundamental within the theory of symbolic interactionism underpinning this study. This data was retrieved from the patient notes held by the CNS.

3.8.2 Interviews

Grounded theory “works with any data – “all is data” – not just one specific data” (Glaser & Holton 2004, online). As such, different kinds of data present different views or vantage points to the analyst (Glaser & Strauss 1967). Single or multiple sources may be used, including interviews, observations, focus groups, life histories, and personal accounts (Goulding 1999). The knowledge and experience of the researcher may also be viewed as a source of data (Glaser & Strauss 1967). The essential component is that “rich data” is gathered (Charmaz 2006) and that a breadth of information is sought to illustrate and explore the phenomena in the widest sense. The most commonly adopted data collection techniques include qualitative interviews. Swanson (1986) distinguishes between formal and informal interviewing. Formal interviews are used in grounded theory and can include both structured and unstructured interview schedules. The unstructured interview enables the researcher to gain first hand information from the point of view of the informant (Goulding 1999). As grounded theory aims to be inductive and allow concepts and themes to emerge naturally from the data, the unstructured interview facilitates this in the early stages of data collection. Glaser (1967) adheres to the view that the research questions must emerge only from the data and not be predetermined. Strauss and Corbin (1990; 1998), on the other hand, acknowledge that tentative research questions are helpful in providing a focus for the research. As time and analysis continues, the interview can become more focused to elicit further information about emerging themes and categories (Glaser & Strauss 1967). The grounded theory interview is shaped and reshaped as data collection ensues and the collected data becomes more refined

(Charmaz 2006). Glaser and Strauss (1967) iterate that no matter the data 'slices' obtained, almost any 'slice' can yield the same necessary social-structural information.

Strauss and Corbin's approach was adopted for this study. This adhered to the requirements of LREC to approve the interview schedule and because time limits for the study required data to be collected regarding the topic area of interest. The interview guide developed for use in the first interviews was based upon broad topic areas identified from the literature review: namely the context and experiences of patients recovering from primary surgery for colorectal cancer. Broad questions were used to prevent closure of avenues of conversation or topic areas. Individuals were invited to describe their experiences to date, prompting if required for further details of the time leading up to and following discharge from hospital. These general questions served to open the interview, to put the participant at ease and to enable a rapport to develop between the researcher and participant. In subsequent interviews and as analysis continued, the interviews became more focused to elicit further information about emerging themes and categories (Glaser & Strauss 1967). Early emerging concepts included a sense of disruption and loss. These concepts were used as prompts for subsequent interviews. Interviews conducted several months after surgery raised concepts regarding repair and restoration. These concepts were then incorporated into interview schedule at the latter stages. Flexibility in the interview process was maintained at all times to facilitate a full exploration of issues.

3.8.3 Time and location of interviews

The first interview was conducted within a month of the patient's attendance at the outpatient department. Participants were offered a choice of location for the interview

and all elected to be interviewed in their own home. The interviews were all conducted at a time convenient for the participant, predominantly during working hours Monday to Friday, although two interviews were conducted at the weekend. The interviews were conducted solely with the patient: with the exception of two patients who requested their spouse was present. A follow up interview was conducted three months later, to elicit the participant's experiences and thoughts over time with regards to their recovery. This follow up interview included emerging concepts arising from preliminary data analysis of the first interviews. Concepts included: a sense of disruption; loss; threats to personal identity. The content of the follow up interview changed every time to refine and fill out the categories and properties (see table 5 for examples of interview prompts).

Interview 1	Q: Could you give me a brief history of what has happened? Prompts: pre diagnosis; experience of diagnosis and treatment; experiences since discharge home.
Interview 2	Q: So how have you been since I last saw you? Prompts: body repair; emotional response; sense of personal identity.
Interview 3	Q: So how have you been since I last saw you? Prompts: body repair (how are they assessing and monitoring progress); independence (in activity, follow up; wanting information; autonomy); nurturing by family and friends.
Interview 4	Q: So how have you been since I last saw you? Prompts: sense of wellness (definition; thoughts for future; priorities); sense of illness (ongoing symptom burden; fears for future; sense of time).

Table 5: Opening question and prompts for data collection interviews

After completing the follow up interviews for patient 1 and patient 2, it became apparent that interesting and valuable data could be obtained by adopting a longitudinal approach to data collection. Between the first and follow up interview, two patients had initiated contact with me to report some concerns about their health and to seek clarification on what action they should take. Both of these patients were directed to seek advice from either their General Practitioner or the CNS. However,

their comments, and the ongoing analysis suggested that the patients' experiences of recovery were continuous and that, as they moved further away from the time of treatment, some aspects of their recovery were not resolved. Therefore, an application was made to the ethics committee for a substantial amendment to the research protocol in order to increase the follow up interviews to a maximum of four over a one year period (Appendix G).

3.8.4 Researcher interview skills

Swanson (1986) highlights the skills required by the researcher when undertaking interviews. This is particularly relevant when considering the use of unstructured interviews. Interpretive, qualitative methods require the researcher to enter the participants world, therefore, the development of a rapport during the interview is essential (Charmaz 2006). Moser and Kalton (1971) also say that researchers need skills of intelligence, understanding and tact, and a deeper knowledge of the subject matter. These factors will assist the researcher to "put the participant at ease" and allow them to speak freely. This in turn will enable the researcher to begin to understand the participant's world, from their perspective (Charmaz 2006).

At the beginning of the data collection period, I had fifteen years of experience of conducting qualitative interviews with people with cancer. During this time, I felt I had developed my skills of developing a rapport and facilitating a meaningful and open discussion of pertinent issues. I had limited detailed knowledge of bowel cancer and the aftercare following primary treatment, but Swanson (1986) recommends that the researcher be "fresh" to the clinical area under study. If the researcher has in-depth knowledge of the area, they may be more likely to overlook the experience and perceptions of the participant, or make assumptions about which issues are relevant.

Whilst much has been written about how to undertake interviews, less attention has been focused upon the impact and consequences for the researcher conducting in-depth interviews (Johnson & Clarke 2003). By the necessity of developing a rapport and enabling the participant to feel comfortable to disclose, the researcher is at risk of "crossing the professional boundary". Dickson-Swift et al (2007) discuss how a researcher's understandings and level of reciprocity can influence the relationship they develop with the participant. The boundaries become more blurred when the researcher interacts with the participant on a personal level. This was pertinent to my study as over time and with subsequent interviews, I developed a deeper and more personal relationship with the patients. I learnt more about them individually, their families; and issues that were important to them. Maintaining a professional role whilst conducting the interviews became more complex as time progressed (see box 2). Another consequence of developing a deeper relationship with the participants related to the nature of the interviews. It became quite difficult on occasion to keep the patient 'focused on task'. Some were more interested in talking generally about their lives, or what my family were doing. In the spirit of reciprocity, they would share information about their family or holidays and I would respond in kind. The professional boundary between nurse and researcher was also threatened during interviews if the patient asked me a direct question regarding their health or care. As Corbin and Morse (2003) comment, participants often agree to participate in research because they want something in return, for example the opportunity to unburden or to seek information. Corbin and Morse (2003) continue that a conscientious researcher will ascertain what the participant is seeking and if possible, will respond either during or after the interview. When asked a direct question in the interviews, I would respond immediately, but depending on the nature of the question I would usually defer to the GP or the CNS. In one instance the patient asked specifically about

other sources of advice or help available to which I agreed to provide a list at the end of the interview.

January 2009

Longitudinal data collection, is it a benefit to developing a rapport, an insight into their world? The down side is that it is hard to know where to draw the line. When I phoned Pt 7 to arrange his third interview, he wanted me to come after work, which suited me as I had an evening meeting. But when he realised I had the meeting and therefore wouldn't be going home he suggested I stay for tea. His wife would make sausage rolls specially! It didn't feel comfortable to do that, but I didn't want to hurt his feelings so I said that I would be eating at the meeting (sort of true but not completely!). He also said I must take some plants from his garden as he will be moving soon after our next interview. It does raise lots of issues and dilemmas. I am now conscious about how I need to start preparing to 'leave' them. I have been a part of their lives on a regular basis and it feels reciprocal, they talk to me and I talk to them. But how do I then re-define the boundaries when I no longer 'need' to interview them?

Box 2: Excerpt from researcher log

3.8.5 Patient diaries

The initial research proposal had included the use of patient diaries, to be kept and completed by the patient throughout the three month period. The aim of the diary was to assist their recall, and to record 'day to day' living rather than relying totally on retrospective recall during the interview (Bytheway & Johnson 2002). This technique of data collection was chosen because it can provide a valuable source of data when extended periods of participant observation are not possible (Jacelon & Imperio 2005). A solicited diary (written for the purpose of research) allows the participant to focus on areas of interest and relevance to the researcher (Elliott 1997). The diary

can provide details of which issues are deemed important by the participant and their attitudes towards those issues (Jacelon & Imperio 2005). Jacelon and Imperio (2005) determine the optimum time period for completion of self recorded diaries at two weeks. They comment that participants may lose motivation to complete diaries at any time longer than this. However in this study it became apparent early in data collection that participants were not completing the diary. It is unlikely the patients were overburdened as they rarely completed the diary from the outset of the study. Two patients commented they preferred to contact the researcher directly, as they were not certain what constituted suitable notations. Therefore the decision was taken to discontinue with the diaries and I agreed with the participants that I would telephone on a monthly basis. It was not feasible to audio record the telephone contacts as they were sometimes initiated by the participant, but detailed field notes were recorded. The content of these telephone conversations were used as prompts in the next interview if relevant to the emerging concepts and properties. The telephone contacts were viewed as supplementary data, and did not replace the regular interview schedule.

3.9 *Data analysis*

3.9.1 Transcription of the interviews

As Silverman (1993) comments, the preparation of transcripts is not simply a technical detail prior to the main analysis. Transcription processes are rarely discussed in detail within research papers; and there is limited guidance within the methodological literature (Easton et al 2000; Fielding 1994). This is of concern as the integrity of the verbatim transcription and researcher notation directly affects the credibility, dependability and trustworthiness of the research (Seale & Silverman 1997; Easton et al 2000).

I decided to transcribe the interviews myself because this would enable me to hear the 'whole story' again which aided recall and understanding of the context. I would also ensure accuracy of reporting thus strengthening the rigour of the study; and adhere to ethical principles of confidentiality of the data. Transcripts do not fully reflect all that occurs in the interview (McLellan et al 2003) and I wanted to be certain that the transcript was an accurate reflection of what was spoken during the interview which has been cited as an issue when using professional transcribers (MacLean et al 2004; Oliver et al 2005).

Halcomb and Davison (2006) suggest that the process of transcription must be congruent with the methodological design and theoretical underpinnings of the study. Transcription refers to the process of reproducing spoken words into text, however, authors have also debated the extent to which nonverbal and emotional aspects of the interview process should also be recorded (MacLean et al 2004). I adopted a "denaturalized" approach to the task, where idiosyncratic elements of speech such as stutters, pauses and non verbal cues are removed (Oliver et al 2005). This approach was deemed appropriate as grounded theory analysis is more concerned with the content of speech rather than the mechanisms of speech. However, I decided to record in field-notes or notate in the transcript if specific idiosyncratic elements appeared to alter the meaning or content of the text. Whilst transcribing, I recorded my personal thoughts and reflections on the interview and data in field note records for each individual patient (see box 3 for example). Examples of participant transcripts are presented in Appendix H.

With reflection, transcribing the interviews personally had a positive impact on my recall of individual's comments and greatly aided the analytical process. A negative

effect of transcribing related to the emotional burden on myself of listening to many hours of patient's narratives and the time costs incurred.

Field Notes, Patient 1 Log
November 2007

This man quite often responds to a direct question with a simple yes or no answer and then continues the conversation on a totally different angle/ track. I am not sure if this is deliberate, I suspect not. It seems/ feels more likely that he has some sort of assumption about what I want to know or am interested in and is answering that. He is perhaps of the generation who do not discuss feelings/ emotions/ coping etc. and is much more comfortable and happy focusing on physical aspects of recovery - that is a point to review.

Do any/ all questions about his emotions/ coping etc. result in a discussion or focus on physical aspects?

Is there merit in reviewing the audio tapes again to consider tone of voice, spacing and timing etc. and whether there is any pause before changing topic?

I made a conscious decision not to share the transcripts or my analysis with the interviewees. One reason for sharing transcripts with participants is to ensure the transcript accurately reflects what they said or meant (Forbat & Henderson 2005). I believe I ensured accuracy of the verbal narrative by transcribing myself. There was only one episode where the speech was inaudible and as it did not appear to alter the meaning of the remaining text, I decided not to seek clarification from the participant. Secondly, grounded theory methodology enabled me to clarify the meanings and my interpretation of the data in the subsequent interviews, therefore I did not feel burdening the participants to read through their transcripts or my analysis was appropriate. Finally, the analysis of the transcripts was ongoing and therefore I had little time in which to ask the participants to review and amend if they wished. Forbat and Henderson (2005) discuss how respondents in their studies were surprised and unsettled by seeing their "speech" in writing which highlighted their ungrammatical comments and idiosyncratic speech. They argue that the researcher has to be very clear as to the reasons for sharing transcripts. As I was uncertain as to whether

viewing their transcript would subsequently influence the content of subsequent interview, I decided to not return the transcripts or analysis to the participants.

3.9.2 Computer software

I used QSR NVivo 7 computer software to assist in data management and analysis. This programme facilitates the management and organisation of large and disparate amounts of qualitative data, from multiple sources (Froggatt 2001; Bazeley 2007). However, the use of computer software programmes does not negate the need for researcher time and attention to the iterative processes of data analysis (Welsh 2002; Bringer et al 2004). Several features within the programme have application within grounded theory: for example, the use of memos to record theoretical propositions or statements; modelling to show cases or test relationships between concepts and categories; "trees" to demonstrate hierarchy and dependency relationships between concepts and categories. Learning to use Nvivo to assist in qualitative data analysis was also a learning objective as part of my professional development within the D Clin Prac. I began to familiarise myself with NVivo in the early stages of the D Clin programme to record my research log and ongoing assignments. Johnson (2006) says a common failing is for doctorate students not to use the programme early enough in their research studies. The use of NVivo also enabled me to illustrate the audit trail of my progress through the D Clin programme and my thesis. This "transparency" of the process is a necessary requirement to demonstrate the quality of the research study, rather than simply relying on the finished product (Spencer et al 2004).

3.10 Coding

Grounded theory analysis involves the researcher moving from inductive to deductive reasoning, deriving statements of hypothetical relationships from the data, testing and verifying them in subsequent data collection and analysis by reviewing the data (Corbin 1986). Induction requires the researcher to move from practice to theory, to have no preconceived hypotheses, to be open-minded and flexible so that the theory emerges from the data (Glaser & Strauss 1967; Strauss & Corbin 1998). The theory can then be tested, enabling predictions to be developed deductively from general principles (McCann & Clark 2003). "Concepts and relationships arrived at through deductive thinking must be verified over and over again against actual data. Initially they are held as provisional and if not supported they are discarded" (Strauss & Corbin 1990:112). The different stages of coding require different levels of abstract thinking. Different coding techniques are used in different phases as concepts and theories are generated and verified. As McCann and Clark outline (2003:13) coding becomes: "A cyclical process; shifting from open to axial and then selective coding and, at times simultaneously coding at several levels". Glaser (1992) and Strauss and Corbin (1998) differ in their stages of coding. Strauss and Corbin (1998) include three stages: open; axial; and selective; which are used in this study.

3.10.1 Open coding

Strauss and Corbin (1990:61) depict open coding as "the process of breaking down, examining, comparing, conceptualizing, and categorising data". Open coding, particularly in the early stage of the research involves microanalysis: the detailed line-by-line analysis to generate initial categories (with their properties and dimensions) and to discover the relationships among concepts (Strauss & Corbin 1998). Open coding aims to shape an analytic frame from which the analysis is developed

(Charmaz 2006). Constant comparative analysis is seen as the first basic analytical step into the data which results in the initial discovery of categories and their properties. Interactions, actions and events which are seen to be similar or related are grouped together under more abstract concepts termed categories. Developing categories is important because it enables the analyst to reduce the number of 'units' which with they are working. Open coding may be conducted on a word by word, sentence by sentence, or segment by segment basis (Charmaz 2006). Each of these methods has merit. Word by word, or line by line facilitate the researcher in opening up the data; "to *mine that data*" (Strauss & Corbin 1998:65, *original emphasis*). This is the most detailed type of analysis and also the most generative. However, this approach would become repetitive over time (Strauss & Corbin 1990) and is not sustainable for large amounts of data (Dey 1999). Coding by segment or paragraph can be used at any time during analysis and is useful when several categories have already been defined and the analyst wishes to develop codes around the category (Strauss & Corbin 1990). Constant comparative analysis enables the data to be coded into emerging themes, and then to be repeatedly revisited and compared with previous incidents in the same and different groups (Hewitt-Taylor 2001). This method facilitates the researcher begin to consider the range of types of categories, their dimensions and properties, and their relationship to each other (Glaser & Strauss 1967).

I firstly read each transcript through several times to gain an overview and recorded initial thoughts. As suggested by Charmaz (2006), I focused on each line or sentence separately to facilitate focusing on a small area of data, thereby limiting the possibility of superimposing my own ideas. This also forced me to consider the fullness in each line of data and be less likely to overlook key phrases or concepts. I considered what words had been used and how, as well as the order of words within

each sentence. Next I reviewed individual words which appeared to be key words, or "stood out" to me. Charmaz (2006) comments that often researcher's thoughts may at first seem to be based more on 'intuition' but in fact may stem from covert actions and meanings within the data. I considered the frequency of specific words and whether the use of a different word would have changed the meaning of context of the sentence or paragraph. As Strauss and Corbin recommend (1990; 1998), I also began to explore possible theoretical differences if an alternative word had been used. This attention to individual words, sentences or lines, and then the paragraph as a whole, enabled me to remain separate from the data and to see with an objective eye whilst still immersing myself in the respondent's narrative and world. Charmaz (2006) highlights the potential for the researcher to become so immersed in the respondent's story that their "worldviews" become accepted without question. The purpose of analysis is to capture the finer meanings within the text whilst still remaining truthful to the overall context and story of the narrative.

By transcribing the interviews, I was able to re-listen to the patient's narrative as a whole. During word and line coding, I 'saw' things that I had not noticed or 'heard' during the actual interview. By devoting attention to individual words, it became apparent how easy it had been during the interview to miss the significance of the word, and how the whole meaning of the line or paragraph could have been changed. Watson (2006) comments on how an apparent inconsequence during an interview becomes highly visible in the transcript, therefore providing a "handle" for analytic meaning. For me, alternating between listening to the audio tapes, transcribing, reading the transcript, and then the detailed analysis all enhanced my theoretical sensitivity to the data.

As I highlighted a word, sentence, or paragraph; I made an annotation to record impressions or thoughts. Quite often these were broad statements or ideas, literally the first thing that came into my head. Then I would allocate a code, recorded as a "free node". NVivo was particularly useful in this process as it enabled me to allocate several codes to overlapping sections of text. In the earlier stages, a section of text would also appear to relate to several codes. Within the NVivo programme, I was able to review large segments of text and observe the various codes attached. Descriptions were given to each node to ensure reliability in the coding strategy adopted, and to assist the audit trail. This became more vital as I continued to code subsequent transcripts. My initial coding strategy was reviewed regularly and general themes or topic areas were noted. As subsequent interviews were coded, constant comparative analysis was undertaken. Codes were compared within the same interview; between different patient's first interviews; between consecutive interviews with a patient and so on. Themes which emerged during open coding provided direction for the literature review. Topics included awareness of body changes; body disruption; the emotional impact of a cancer diagnosis. The chronic illness literature was reviewed, in particular the theory of biographical disruption.

3.10.2 Axial coding

Axial coding is an intermediary set of coding procedure suggested by Strauss and Corbin (1990), which deviates from the Classic Grounded Theory method proposed by Glaser and Strauss (1967). The purpose of axial coding is to begin to reassemble the data that was fractured during open coding. Categories are systematically developed and linked to their subcategories to form more precise and complete explanations about phenomena. The "focus is on specifying a category (*phenomenon*) with regards to the conditions that give rise to it; the *context* in which it

is embedded; the action/ interactional *strategies* by which it is handled, managed, carried out; and the *consequences* of those strategies" (Strauss & Corbin 1990:97, *original emphasis*). Open and axial coding are not separate sequential steps and so therefore the researcher can continue to code for properties and dimensions whilst simultaneously developing relationships between concepts. Questioning the data will help "contextualise a phenomenon, that is, to locate it within a conditional structure and identify the "how" or the means through which a category is manifested" (Strauss & Corbin 1998:127). Strauss and Corbin (1990:77) recommend asking questions of the data to inform the process of coding: such as "Who? When? Where? What? How? How Much? and Why?" These questions were helpful in developing and filling out the properties of codes and categories. For example, the properties of symptoms were relevant to the meanings attributed by participants, and the actions they took in response. This directed the literature review to include the characteristics of chronic illness; co-morbidity and factors influencing the presentation and diagnosis of colorectal cancer.

Strauss and Corbin (1990) advocate the use of the "*paradigm model*" as an organisational scheme or framework to explore and test links and relationships between subcategories and categories in axial coding. Without using the model, there is a danger the emerging grounded theory will lack density and precision. Attention to structure will enable the analyst to learn why events occur; by creating the circumstances in which problems, issues and events are situated or arise. Process denotes the action/ interaction of people over time, in response to certain problems or issues. By combining the two, the analyst is able to "get at some of the complexity that is so much a part of life" (Strauss & Corbin 1998:127). The paradigm model is an analytic stance that helps to systematically gather and order data in such a way that process and structure are integrated (Strauss and Corbin 1998).

Figure 2: Paradigm model (Strauss and Corbin 1990)

At the centre of the model is the phenomenon. Strauss and Corbin define the phenomena as "The central idea, event, happening, incident about which a set of actions or interactions are directed at managing, handling, or to which the set of actions is related" (Strauss & Corbin 1990:96). The components of the paradigm model include conditions which are the structure, set of circumstances or situation leading to, or influencing the phenomenon. Causal conditions are usually an event or happening that influences the phenomena and may include time, place, culture, beliefs, and power. The causal conditions identified during axial coding highlighted the importance of power, expertise and authority demonstrated by health professionals and health service practice. These themes were duly incorporated into the literature review to further refine, strengthen and integrate the analysis. Intervening conditions may mitigate or alter the impact on causal conditions, for example unexpected events which in turn influence actions/ interactions. Contextual conditions are a specific set of properties that pertain to the phenomenon and are located along a dimensional range. Context may also relate to the set of conditions influencing action/ interaction. Strauss and Corbin (1990) emphasize it is important the analyst focuses on the complex interweaving of the different types of conditions. Actions/ interactions may be strategic and purposeful, or they may be routine which represent a more habitual way of responding. Actions/ interactions are also processual, in other words, evolving. The final component of the paradigm model is consequences which may relate to people, places or things. Consequences can result in an event or an action/ interaction. Importantly, they can become part of the

conditions for future actions/ interactions. The paradigm model served as a framework upon which to consider the properties and categories within axial coding. Questioning the data and identifying links was facilitated by considering the contextual and influencing properties for the phenomenon. In turn, this enabled a clearer relationship to be identified between the categories, and ultimately focused the analysis upon the emerging core category. As analysis became more refined and patterns began to emerge between codes and categories, these were documented in memos. Bazeley (2007) suggests developing several types of memos to distinguish between theoretical discussions; coding practicalities; personal reflection etc. The use of differing memos facilitates the audit trail and analysis process. I took two sections of text that had been labelled as a category and then compare them. As each new piece of text was labelled as a category, this was also compared to previous categories. This detailed and rigorous process of constant comparison both advances the conceptual understanding and makes analysis more explicitly theoretical (Charmaz 2006).

3.10.3 Selective coding

Selective coding is the process of integrating and refining the theory, and requires a higher and more abstract level of analysis. Strauss and Corbin (1998) suggest several techniques to aid this process including: writing the storyline; using diagrams; sorting and reviewing memos. These techniques help visualise relationships, establish consistency and support inductive and deductive thinking (McCann & Clark 2003). The first step in integration is the identification of a central category; the core category. This core category has analytic power i.e. it pulls other categories together to form an explanatory whole (Strauss & Corbin 1998). Strauss (1987) provides 6 criteria for choosing a central category:

1. It must be central. All other major categories can be related to it.
2. It must appear frequently in the data
3. The explanation that evolves by relating the categories is logical and consistent. There is no forcing of data.
4. The name of the central category is sufficiently abstract to then research in other substantive areas to develop a more general theory.
5. As the concept is refined analytically through integration with other concepts, the theory grows in depth and explanatory power.
6. The concept is able to explain variation as well as the main point made by the data.

The next step is then to develop the core category in terms of its properties and relating the subcategories of the core category (Strauss & Corbin 1990). Once the theoretical scheme has been outlined, the analyst then refines the theory by checking for internal consistency and for gaps in logic. Poorly developed categories are “filled in” and excess categories are “trimmed off” through further theoretical sampling (Strauss & Corbin 1998:156). This process can continue until no new properties or dimensions emerge from the data and, therefore, theoretical saturation is achieved. The core category emerged early in the analysis but required subsequent interviews and analysis to refine and saturate the categories and properties. Particular focus was needed to explore variations in the core category as experienced by participants. Not all exhibited all the properties to the same degree, and therefore attention was given to testing and trying to refute some categories. When this was no longer possible, and all categories were relevant to the central category, it was determined that the core category had emerged. The use of diagrams and theoretical memos were helpful in the process due to the large volume of data and range of categories. (see Appendix I for examples of coding categories). The literature was reviewed to

support the emerging core category. Conceptual links were identified with the literature on chronic illness and the illness experience; how a cancer diagnosis disrupts a previously familiar and taken for granted life, and threatens a sense of personal identity.

3.11 Methodological rigour

Glaser and Strauss (1967) propose fit, workability, relevance and modifiability as appropriate indicators of judging the rigour of a study. Fit relates to how the categories should emerge from the data and not be selected from a pre-established theoretical perspective. The theoretical concepts should match the phenomenon and incidents of interest. Workability means that theories should provide predictions, explanations and interpretations of what is going on in the area under study. Relevance means that theories should be relevant to the area they purport to explain; focusing on the emerging core problems and processes. The analytical concepts must be able to address the real concerns of participants, not those of the researcher. Finally, modifiability means that a grounded theory might undergo changes when new data emerges i.e. the theory has capacity to alter or expand to accommodate new data (Glaser & Strauss 1967). Strauss and Corbin (1998) highlight that different options are available to evaluate a study and that the method chosen will reflect the specific aspect of the research that is being studied. They add two criteria to those proposed in the Classic Grounded Theory text: criteria of reproducibility and generalisability (Strauss & Corbin 1998). Hall and Callery (2001) argue that both Glaser (1978) and Strauss and Corbin's (1990, 1998) criteria for rigour are problematic because they are based on the ontological assumption of critical realism. This position believes that reality exists and is driven by natural laws that can be only incompletely understood (Guba 1990). As such, Strauss and Corbin

place emphasis on theoretical sensitivity and the researcher's manipulation of the data to yield explanations that best reflect the reality that is being studied (Hall & Callery 2001). This stance does not examine the researcher's effect on data construction or address power and trust relationships. As an 'antidote' to this, qualitative researchers propose the incorporation of "reflexivity" into the research process (Hall & Callery 2001). The purpose of reflexivity in part, is to enhance the credibility of the study findings by accounting for the researcher's values, beliefs, knowledge and biases (Cutcliffe 2003). Koch and Harrington (1998) contend that the entire research process is reflexive and provides answers to the question of what is happening while researching. Evaluation criteria may be generated within the research project itself, through detailed and contextual writing, and a reflexive account of the actual process. Charmaz (2006:188) defines reflexivity as "the researcher's scrutiny of his or her research experience, decisions, and interpretations in ways that bring the researcher into the process and allow the reader to assess how and to what extent the researcher's interests, positions, and assumptions influenced inquiry. A reflexive stance informs how the researcher conducts his or her research, relates to the research participants, and represents them in written reports." The adoption of a reflexive stance by the researcher is seen to enhance theoretical sensitivity (Gardner 2006). Within the study, strategies to attend to rigour include regular supervision from an experienced grounded theorist, the keeping of a reflective researcher's log and field notes, and wide reading of the literature. Memos were used to record reflections on theoretical aspects, data analysis, and the researcher's impressions. Participants own words were used to illustrate the research processes of data analysis and theory development.

3.12 Summary of chapter

This chapter has described research paradigms and the development of Grounded Theory. Grounded theory is the chosen methodology for this study because it incorporates a symbolic interactionism perspective, where the emphasis is upon the natural world of human behaviour. This methodology develops inductively to derive a grounded theory about the phenomena of interest. This methodology is appropriate to explore the experience of recovery as grounded theory focuses on the everyday experiences of individuals in their social world, as they construct and reconstruct reality through ongoing interaction. This is pertinent as the focus is upon the individual's perspective, using their narratives to explore their experiences in their home environment and within their natural social world.

Ethical approval for the study was granted by the local research ethics committee. Twelve individuals receiving surgery and no adjuvant treatment for colorectal cancer were recruited from a cancer centre. Each individual participated in three or four semi-structured interviews, at three monthly intervals for a total of twelve months. The interviews were transcribed verbatim and subject to inductive data analysis using the constant comparative method as proposed by Strauss and Corbin (1990; 1998).

CHAPTER 4: RESULTS

4.1 Introduction

The purpose of this chapter is to introduce the results of the study in accordance with the paradigm model developed by Strauss and Corbin (1990; 1998). The results are presented in order to depict the grounded theory *Restoring the Self: a Sense of Wellness*. The grounded theory has three phases: Disrupting the Self; Repairing the Self; Restoring the Self: a Sense of Wellness. The categories and properties of the phases will be discussed to illustrate how the theory has emerged through inductive analysis. The three phases are presented separately; each including categories and properties to provide a clear audit trail of the emerging theory and the elucidated conclusions.

Excerpts from participant narratives are used to illustrate how the data analysis is grounded in the data and to emphasise the richness and diversity of the data. Data extracts are denoted in speech marks and italic, with the participant number/interview number in brackets, for example participant 4, interview 3 is (4/3). References are made to the literature to support the findings, however, the main literature review was undertaken after the core category had emerged (Glaser 1992) and used to further refine the emerging theory (Strauss & Corbin 1998).

4.2 Study participants

Twelve individuals of varying age and gender participated in this study (table 6). They were all recruited from the same oncology centre from the caseload of two colorectal surgeons. Nine participants completed four interviews; two participants

completed three interviews; one man withdrew after interview 2 because of poor health. Two individuals (pt 7, pt 8) were interviewed with their spouse present at their request. Several had co-existing health morbidities including diabetes (n=3), osteoporosis (n=3), arthritis (n=2) and irritable bowel syndrome IBS (n=2).

Participant	Age	Gender	Consultant	Living context	Co-morbidity	Interviews
1	87	M	1	Alone	Arthritis	4
2	83	M	2	With spouse	IBS	2*
3	56	F	1	With spouse	None	4
4	70	F	1	With spouse	Osteoporosis	4
5	80	F	1	Alone	IBS	4
6	81	F	1	With daughter	Diabetes, osteoporosis	4
7	65	M	2	With spouse	None	4
8	76	F	2	With spouse	Arthritis	4
9	69	F	1	With spouse	Diabetes, osteoporosis	4
10	50	M	1	With spouse	None	4
11	68	F	2	With spouse	Diabetes	3**
12	71	M	1	Alone	None	3**

Table 6: Characteristics of study participants

* Participant 2 withdrew following interview 2 because of poor health

**For theoretical sampling purposes, Participant 11 and 12 entered the study 3 months after surgery

4.3 Phase one - disrupting the self

Disrupting the Self is the first phase in the participant's illness experience. This phase occurs in the time leading up to diagnosis, when the participant first becomes aware of a change in their health. This phase continues as they seek medical advice for their needs, proceeding through referral to secondary health care services and culminating in surgical treatment for their colorectal cancer. The conceptual term *Disrupting the Self* illustrates how the illness experience threatens aspects of personal identity, through challenging previously held beliefs and assumptions about the world. *The Self* is maintained and evolves through daily interactions within the lived world (Williams & Bendelow 1998), and can change from a relative stable core to a series of identities, subject to repeated reflection and examination (Flanagan & Holmes 2000). The illness experience may present a crisis which disrupts the familiar and predictable world (Freund & Maguire 1991). *Disruption to Self* includes categories of: body disruption; medicalisation within secondary health care services; emotional disruption and functional disruption (table 7).

Category	Subcategories
Body disruption	Acute symptoms Chronic symptoms Medical interventions
Medicalisation within secondary health care services	Treatment pathway Body handover Nomenclature Loss of dignity
Emotional disruption	A cancer diagnosis
Functional disruption	Loss of valued roles

Table 7: Categories and subcategories of disruption to self
(pre diagnosis and treatment)

4.3.1 Body disruption (pre diagnosis)

For participants in this study, the pre diagnosis phase of their illness involves a change in their bodily function or integrity. Most become aware of these bodily changes through the experience of physical symptoms. No participants were diagnosed via the Bowel Screening Programme (Hewitson et al 2008). These changes in body integrity are further compromised by the medical investigations required to elicit the cause of these physical symptoms. Mathieson and Stam (1995: 294) propose that physical symptoms signify a "rite of passage from good health to illness". Corbin (2003) discusses the use of the word symptom as a medical interpretation; the individual will talk in terms of differences or difficulties. "Persons do not talk a language of symptoms" (Corbin 2003:258); instead they will use language which describes how the illness is making them feel or affecting their daily life. For example, one woman talks of how her *"insides weren't working well"* (4/1); another participant talks of how *"everything was very dark when I went to the toilet."* (11/2). Data excerpts are presented using terms adopted by the participants, but the analysis includes the word symptom to enhance the clarity of explanation. The category of body disruption includes the properties of acute symptoms; chronic symptoms; medical intervention.

4.3.1.1 Acute symptoms

Some participants' experience acute and specific symptoms. One man describes a singular event which occurs suddenly and is unanticipated:

"I'd enjoyed good health and a good holiday and I didn't feel I had any medical problems. When I came home, I went to the toilet and when I opened my bowels there was blood in the toilet bowl and I was quite disturbed by that." (10/1)

This man feels very well and has no forewarning that anything is amiss with his body. Returning from holiday, he is relaxed and off guard. Within this context of good health, the suddenness of the bleed is perceived as an abnormal event and causes great alarm. His body is seen to fail from within, threatening his feelings of confidence and trust in knowing his own body. Whilst the physical body serves as the primary mechanism through which a person lives within the world, it is the process of higher cognition which interprets this 'lived-in' world (Leder 1990). A single episode of an acute symptom may therefore be perceived as a significant threat which justifies the need to seek advice. Tobin and Begley (2008) describe how such an event becomes the "point of focus"; the pivotal point which marks a severance of normalcy. From a medical viewpoint, rectal bleeding alone is a poor positive predictor of colorectal cancer (Hamilton & Sharp 2004), however as an indicator for participants in this study, it is perceived as something very serious.

4.3.1.2 Chronic symptoms

More commonly, participants' experience an insidious onset of a combination of symptoms. Insidious symptoms tend to be more subtle, less visible, and harder to quantify. They may be unacknowledged or ignored for a period of time as this woman explains:

"Well for a start I did have, I was incredibly tired. I had had a hip replacement the year before and you know how you kind of blame things like that and also when I was in the hospital my insides weren't working very well when I came home and I thought it was because I had had all this done and um, I just seemed to have diarrhoea all the time and in the end I mentioned it to the doctor and, you know, just in passing and

didn't think anything of it and she said well is there a sign of any blood? And I said I don't know because I haven't looked and she immediately took a sample and um, sent it off and that was the start." (4/1)

This woman describes multiple experiences which added together have a significant impact on her overall feeling of illness. Her symptoms of tiredness and diarrhoea are attributable to previous surgery, as they occurred at a similar time. She initially adopts a common sense explanation, perhaps because she does not realise the significance of her experiences or because she does not want to consider a more serious cause. The non-specific nature of the symptoms and other plausible explanations make it difficult to recognise the seriousness of symptoms. Perception of a failing physical body is complex for those who have insidious changes and action is only prompted when the symptoms become prevalent over time, or begin to disrupt activities of daily living. As a result, participant confidence and trust in their body awareness skills is shaken: *"They said I could have had it for years you know"* (7/1). In some cases, participants' remain unaware of a problem and body failure is detected through a routine visit to the GP for existing co-morbidities.

As can be seen from table 8, all the participants' experience multiple symptoms with diarrhoea, tiredness and anaemia most prevalent.

	Participant ID											
Presenting symptoms	1	2	3	4	5	6	7	8	9	10	11	12
Rectal bleeding			✓		✓		✓			✓		
Positive occult blood			✓									
Anaemia			✓			✓		✓	✓		✓	
Diarrhoea	✓	✓		✓				✓			✓	✓
Abdominal pain			✓						✓			✓
Wind	✓	✓	✓		✓							
Indigestion		✓	✓									
Fatigue			✓	✓		✓		✓	✓		✓	✓
Weight loss			✓				✓	✓				
Abdominal mass								✓				
Loss of appetite								✓				
Referred via 2 week rule		✓	✓	✓			✓	✓	✓	✓		

Table 8: participant ID and presenting symptoms

4.3.1.3 Medical interventions

Medical interventions also threaten the integrity of the physical body. The participants' submit to pre-operative investigations which induce intense and uncontrollable bowel stimulation and evacuation. Bowel control is a normal feature of adult life. Therefore, disruption caused by involuntary release of flatulence and faeces causes' distress, as it demonstrates the loss of reliability in the body. Nil by mouth protocols may be unfamiliar and disrupt existing dietary routines, undermining control for those with co-existing diabetes: *"I was worried about how my blood sugar*

might react; you know, by not eating for all that time." (6/1) Significant body disruption is induced by anaesthesia as this man describes:

"I don't know what it did but it almost sent me out of my mind to be honest with you. I didn't know what time of day it was, I couldn't see clearly, I was speaking a load of rubbish, I was vomiting." (12/1)

This man recalls an unpleasant experience following surgery where his experiences of altered consciousness emphasises how little control he has over his body. His reaction to the medication is extreme and causes him to lose mental faculties of cognition, speech and sight. This temporary loss of primary body functions disables him and places him in a position of vulnerability. At the time when health professionals induce his disablement (albeit with good intentions), he becomes reliant upon them for safety and support. The culmination of this disruption is to highlight the failure and loss of a predictable and trustworthy body. The previously familiar body may have been taken for granted and these new experiences undermine feelings of personal control and trust.

4.3.2 Medicalisation within secondary health care services

In this study, medicalisation of the illness experience is the process by which participants come under the control and authority of the health professionals and health services. Participants enter the health service for investigations and treatment, where their experiences are influenced by interactions with health professionals. Health care services provide the environmental context within which these interactions occur. The structure and processes within the health service emphasise that power rests with the health professional and the individual participant

has limited personal autonomy. Medicalisation is directed by a prevailing concept of the biomedical model which gives less attention to the individual's subjectivity. Participant's narratives suggest interactions are often focused around the disease process and treatment, with power and authority vested in the expertise of the health professional. The category medicalisation includes properties of treatment pathway; trust; professional authority; dignity.

4.3.2.1 Treatment pathway

Medicalisation is evident in participant's description of progression through the treatment pathway. Eight participants were referred to the colorectal service under the Two Week Rule by their GP (DoH 2000a). Upon entry to secondary health care, all participants then describe their experience of a rapid treatment pathway:

"Literally it was, I think I must have been fast tracked, it was so quick." (9/1)

This woman uses the term "fast track" which implies that access to rapid treatment is expedited and she has little forewarning prior to receiving her outpatient appointment card. Several participants describe rapid progression through an organised system of technical procedures, which serve to stress the urgency and potential seriousness of their situation. There is *"no time to waste"* (10/1). This rapid transition from one procedure to another seems impersonal and automated as this man suggests:

"If you are treated, a bit like being in the army, that would be awful and it would be so easy to do that, especially when they have masses of people to treat." (12/2)

Participants' are reluctant to proffer negative comments, although this man suggests a subtle criticism. He perceives the prime concern of health services is to treat as many people as quickly as possible and the needs of the individual have secondary importance. He offers a comparison to the army, suggesting that hierarchical authority, routines and adherence to the rules are the priority. The rapid transition through the health service and lack of attention to individual needs can weaken feelings of personal control. Power is seen to rest with the health professional as this man describes:

"You have to take it; you had to do what they tell you otherwise it is not worth going."

(1/1)

This elderly man is aware that, upon entry to the hospital, the health system is in control and that failure to adhere to the recommended regime could jeopardise his subsequent management. He is required to concur with the pattern of treatment imposed by the health professional and adopts a passive repose in the sick role (Parsons 1951).

The rapid treatment pathway confirms medicalisation through a biomedical focus on diagnosing the disease and the primacy of the physical body. Less regard and time is given to the emotional or psychological experiences of participants. Rier (2000) talks of a "telescoped trajectory" where the patient has little opportunity to reflect on, or prepare for, the forthcoming processes. Experiences are characterised by immediacy with the physical body and a reliance on health professionals to ensure physical safety and ultimately life. Participants' experiences of a rapid treatment pathway continue up to the point of discharge, as noted in the following data extract:

"It, well I mean it all happened so fast I didn't even realise I had been in hospital and out again, you know what I mean, things were happening so quickly." (4/1)

This woman describes an experience common to the majority of participants. Discharge decisions are made by the hospital team in response to health service demands. Participants' rarely feel involved in discussions regarding their readiness for discharge and, as such, many feel unprepared as this woman describes:

"I mean they didn't actually ask me if there was going to be somebody at home to look after me. I remember the day after the op when they came round to see us and that was the day I was feeling pretty lousy but it was clearly stated, well you're doing fine, go home tomorrow." (11/2)

Although she feels unwell from the anaesthetic and surgery, this woman clearly recalls the team visiting her and telling her she will be going home. From her perception, the decision is made without her involvement and with little consideration of her recuperative needs once home. The health professional fails to appreciate or acknowledge that she is feeling unwell. Failure to discuss her home situation prior to discharge confirms a focus upon the medicalisation of the illness experience as this woman's subjective experience is not assessed. From a medical perspective, the surgery is complete, initial body repair is progressing and, therefore, this woman no longer requires inpatient services from the hospital.

4.3.2.1 Body handover

Upon referral to secondary health care, participants' are required to handover responsibility for their self-management to the health professionals. Having a sense

of trust in the health professional eases this process of body handover for the participant. Schou and Hewson (1999) discuss how public perceptions of the hospital can influence a person's feelings and behaviour at this time. Participant narratives are replete with comments of positive regard (see box 4).

"He has done a good job on me..." (1/1)

"The team were very, very good, I couldn't fault it." (3/2)

"I feel we do have, and I hope that it continues, I feel that we do have quite a good health service to be honest with you.... You read about [treatment centre] in all sorts of documents and papers, it's very good up there." (11/4)

Box 4: Excerpts from narratives regarding trust in health professionals

Participants' express layman's knowledge of the hospital's good reputation within their social community: *"They've got a marvellous name, haven't they?" (7/1)*. Reiterating these positive accolades serves to instil a sense of confidence and validates their decision to handover responsibility to the health professional. Specifically, faith in the surgeon is important, as described by this man:

"He is a wonderful chap, he exudes confidence, he is the sort of person you would want your life in his hands... We did feel confident that we could cope with, not desperate, we were concerned but optimistic. We had a full belief and trust in the hospital team." (10/1)

This man describes how the surgeon demonstrates a powerful sense of self confidence which, in turn, instils confidence in the man. The surgeon's expression of self confidence and professional authority is reassuring to this man and his wife.

They believe the surgeon is competent to practice and will ensure the participant's safety. Having faith in the surgeon, as the expert with the relevant technical knowledge, acts as a counterbalance to the fear and anxiety they feel regarding the cancer. They feel some anxiety regarding the forthcoming operation, but the attributes of the surgeon confirm their decision to entrust the surgeon with responsibility.

Having trust in the surgeon to perform the surgery and cure the cancer is evident for participants, even if they have not met the surgeon: *"I wouldn't know what [consultant surgeon] looked like to be quite honest"* (6/2). Many pre operative investigations and outpatient appointments are conducted by members of the team rather than the consultant. As such, individuals may have limited time to develop trust in a particular individual (Hurley et al 1995; Zerwekh 1998). However, this appeared to have little impact for participants' in this study. Only two individuals could not recall having met the consultant surgeon; which may be true, or may reflect the significant number of new individuals they met during a brief period of time. Confidence in the surgeon is, therefore, partly maintained by lay knowledge within the local community or by an inherent belief in the surgeon as an expert, acting with beneficence. In this group of elderly participants', it is likely that Western cultural beliefs of the hierarchical authority invested in the medical professional with the surgeon as the figurehead, have an influence.

4.3.2.3 Nomenclature

One way in which the health professional demonstrates authority is in their use of nomenclature. Participants' often struggle to comprehend the unfamiliar and medical language used by health professionals as explained by this woman:

"So they said that they had done the analysis and it was A, B, C and something, it was B something so there is no ..."

Interviewer: "What did they say the A, B, C means?"

"Well they didn't tell me but he said B means it is alright so um.." (5/1)

This woman is able to recall some details of the consultation she had regarding the results of her surgery. She describes an impersonal and objective consultation where "they said", "they had done". Her experience illustrates a biomedical model which emphasises the importance of diagnostics and histology staging for cancer. The health professional does not explain the implications of the results, nor do they attempt to assess how much this woman has understood. As a result, she experiences an objective and impersonal consultation in which her personal subjectivity is not enabled. In response, this woman focuses on the information she does understand which is that her results are satisfactory. The medical terminology about disease staging and mechanics of surgical treatment can be complex. The individual may struggle to make sense of this information and is dependent upon the health professional to navigate the unfamiliar language. Mathieson and Stam (1995) discuss how a focus on medical language reinforces the individual's new identity as a patient and emphasises the medical diagnosis as prime concern. Participants' may perceive the use of medical terminology as indicative of the health professionals' status as the expert. However the participant can be left feeling uninformed if the health professional makes insufficient attempts to ensure they understand the terminology.

Participants' also comment on the health professionals tendency towards language of diminution such as "a small growth"; "a small problem"; "a polyp" (see box 5).

"He found that I had a small, a very small cancerous growth on the bowel.." (1/1)

"They tell you what you have got and it's a polyp and they take it away for histology." (3/2)

"I was shocked when he said there was something there and then he said don't worry about it, it could be a cyst." (8/2)

"I think they said it was a small tumour and that I needed some surgery." (11/2)

Box 5: Excerpts from narratives illustrating language of diminution

The use of minimising language is a dominant feature in the diagnostic and treatment phase (Schou & Hewison 1999) and may downplay the importance or seriousness of the situation. Health professionals may use this language to emphasise the curative potential for the diagnosis. Ambiguous terminology, such as "cyst", "polyp", or using minimising language can protect the health professional from difficult or searching questions from the participant. The use of minimising language is reassuring to the participant, as they now perceive their problem is relatively insignificant, and the urgency associated with the earlier treatment pathway is no longer necessary. This language used by health professionals can, therefore, transform the participants' understanding; described by Silverman (1987) as a redefinitional process. Difficulties will arise however, if the participant's new understanding and interpretation is inaccurate (see section 5.4.3.1).

4.3.2.4 Loss of dignity

Dignity is concerned with privacy, respect and being treated as an individual (Woogara 2005). In the context of colorectal cancer, dignity includes aspects of the physical body because diagnostic tests and treatment are personal and invasive. An

area of the body has to be exposed, an intimate area often not seen by others. This exposure takes place in a room full of machines and under the gaze of the people conducting the tests. Four participants' talk at length about their distressing experiences during colonoscopy investigations as illustrated by this woman:

"When I was taken through there were two people, there was a female on this side of me and a male on this side of me and he said i am now going to, and I think he said sedate you, it wasn't clear, so then it went on. I received some information before hand where you will be given, you will be sedated but some people have a, and I don't know what they call it but it is a bit like when you have a baby and they put something, the gas and air, maybe I should have been given that, maybe I should have asked for it but I was in, it was so painful and eventually the man at this side of me said to the person who was watching what I assume was a television set, I didn't look, said to her shall I go for, and mentioned somebody's name and she said no, it's nearly finished now." (8/1)

This woman's experience of the colonoscopy is impersonal as she is "taken through" to the treatment room where two attendants wait for her. These attendants offer no introduction and proceed straight on with the procedure. The male attendant offers instructions but the participant cannot hear him, and he does not verify if she has understood. The implication is of a procedure where routine is paramount and the participant has to submit for this investigation. This seemingly impersonal approach fosters a sense of vulnerability in this woman, perhaps exacerbated by the exposure of a private area of her body in front of a male attendant. Her vulnerability is increased further when the information she received prior to the investigation regarding sedation is proven to be inaccurate. As the procedure continues and it is evident she is in pain, there is no attempt to offer further analgesia or comfort

measures. Her experience fosters a belief in the primacy of the physical body rather than the dignity of the individual. She questions whether she was responsible for asking for analgesia, highlighting the ambiguity regarding who is responsible for her comfort during the procedure. One attendant attempts to respond to her distress but is prevented from seeking advice by the second attendant. The strongly conveyed message is that power rests with the attendant and the investigation must be completed even at the expense of her comfort. This woman's autonomy is eroded as she is unable to express her feelings to the attendant and she has no authority to halt the colonoscopy. Her trust in the benevolence of the service is threatened as the information received prior to the investigation is inaccurate. Negative experiences create feelings of apprehension and fear as colonoscopies will become a regular feature of future life.

Submission to medical procedures can create an imbalance of power, resulting in patients feeling vulnerable (Matiti & Trorey 2004). Autonomy is threatened as the individual has to submit to personally invasive and physically distressing colonoscopies. The literature makes reference to hospital routines abounding with examples of poor attention to patient privacy (Walsh & Kowanko 2002). It is likely that the majority will accept a temporary loss of privacy in return for potentially curative treatment; however, health professionals must be mindful of the psychological impact of hospital practices and consequences for patient autonomy and dignity.

4.3.3 Emotional disruption

4.3.1.1 A cancer diagnosis

Receiving a diagnosis of cancer creates mixed emotions including shock and disbelief. Participants' experience a moment of time standing still as they attempt to make sense of the news they have received: *"It stops everything."* (3/1). Many have suspected cancer, but confirmation is still a shock: *"It really hasn't sunk in yet."* (7/1). Others experience relief that they finally have confirmation of what they suspect: *"It was simply a relief to know what was wrong."* (6/1). The varying emotions and initial reactions are indicative of the emotional disruption caused by the diagnosis. Individuals may feel overwhelmed with emotion and need time to contain and understand their response as this woman describes:

"I didn't actually want to find out anymore, maybe a bit like head in the sand but I just didn't really want to. I knew what was wrong with me, I just wanted to get back and done, I didn't really want to know more about it." (3/1)

There is an element of avoidance or denial in this woman's narrative. This may be an appropriate response in the early stages to overwhelming news of a serious life threat. She reacts to her feelings by focusing on actions to remedy the situation, to remove the cancer. McVey et al (2001) suggest that an individual can reduce fear by limiting the amount of traumatic information processed, and in turn, maximise feelings of personal control. Thoughts about cancer can raise fears of a lingering death, filled with disability and pain. Treatments are perceived as unpleasant, uncertain and causing as much disruption as the cancer itself. Cultural and personal views of cancer will influence how the individual responds. Three participants' mention relative's experiences of cancer and how this influences their own understanding:

"Well my father had prostate cancer and by the time it was diagnosed it was too late to treat and he died. My instant reaction was that I obviously knew I had to see my GP". (10/1)

This man is aware a prompt decision to seek medical advice will offer him the best opportunity to have his cancer treated and he is determined his experience will be different from his father's. A young woman (aged 53) remembers how twenty five years previously her mother had died from inoperable colorectal cancer after ignoring symptoms:

"I was horrified when, because it had been left so late that the pain and distress, it was just terrible which has always made me very, very frightened of this and of course probably made me more frightened when I knew what I had got, it probably actually was even more frightening because all I could remember was the absolute terrible experience that my mother and myself had gone through." (3/1)

This woman's memories have not dissipated over time and she recalls vividly the distress she and her mother experienced. As she now finds herself facing the same diagnosis, these memories take on a renewed vigour as they once again they become realised. The time of diagnosis is a period of uncertainty regarding the nature of the illness and the treatment plan. Reviewing past family experiences can influence the thoughts and behaviour of participants', which may be channelled towards actions to ensure a positive outcome.

4.3.4 Functional disruption

4.3.4.1 Loss of valued roles

Changes in physical function, as a result of illness, prevent the participants' engaging in their usual roles and as such threaten their feelings of self identity. Limitations imposed by the illness can prevent them from fulfilling roles such as a worker, a spouse or a parent, for example. Being unable to participate in usual roles may lead the individual to withdraw from their social world, resulting in isolation. An illness which begins with an insidious onset often causes subtle changes to physical functionality, developing slowly over time. In the early stages, association with older age or a busy life can enable these changes to be dismissed or accommodated into daily life: *"Well I was slowing down anyway."* (8/2). Physical limitations impact upon the functional roles people are able to maintain. Life arenas where it is harder to accommodate illness will include those undertaken in the social environment, for example individuals may have to take time off from work. This causes disruption within their social environment and draws attention to the individual. Those participants' who are working recognise with hindsight that they are becoming less productive:

"I'd been getting more and more tired, and just couldn't put the hours in." (12/2)

Many participants' have co-existing morbidities which offer prior experience of modifying activity and social roles. For example, those with osteoporosis are conscious of modifying physical activity to ensure they do not exacerbate their potential disability. The illness can cause physical changes which negatively affect the functional self. Low energy levels can lead to low stamina having a detrimental

effect on an individual's ability to perform. Life at home is threatened as the individual has to adapt their usual roles and activities.

4.3.5 Summary of disrupting the self

Colorectal cancer causes disruption to many aspects of the self. In the time prior to diagnosis, the integrity of the physical body is threatened by the cancer within and from external assaults from hospital investigations. The failing physical body has an emotional impact on the illness experience as the individual suffers a loss of confidence and belief in a trustworthy body. Entry into secondary health care services further threaten self identity by perpetuating a system where medical authority and expertise is valued and assumes control, and subjective and personal authority is less revered. These interactions between the participant and health professional emphasise the dominance of medical power, creating a degree of dependency within the participant. Receiving a diagnosis of cancer creates emotional disruption which threatens the self and identity by highlighting mortality.

4.4 Phase two - repairing the self

The second conceptual phase of the participant's illness experience is termed *Repairing the Self* and takes place after their discharge home from hospital. In this phase of *Repairing the Self*, the individual engages in the actions and interactions needed to put the Self back into working order. The aim is to make good the damage which has been caused by the cancer and treatment. *Repairing the Self* is more than repair of the physical body, although this may be the priority at the outset. The cancer has also disrupted aspects of the self by threatening the individual's

perception of personal control and authority. *Repairing the Self* requires consideration of these changes to self identity, to precipitate actions which aim to restore a sense of confidence and personal control. Behaviours are influenced by interaction within the social environment. *Repairing the Self* includes categories of repairing the body; nurturing; reclaiming control; sense of loss (table 9).

Category	Subcategories
Repairing the body	Resuming activity Body monitoring Comparing
Nurturing	Family and friends
Reclaiming control	Expression of voice Follow up Information seeking
A sense of loss	Apportioning blame

Table 9: Categories and properties of repairing the self

4.4.1 Repairing the body

Repairing the body is concerned with restoring physical integrity and having a body which is once again functional. Repair takes time and the participants' develop skills of body monitoring by which to assess their progress. The individual may seek comparisons against which to gauge success. The categories for body repair include resuming activity; body monitoring; comparing.

4.4.1.1 Resuming activity

Resumption of daily activities is a measure of success of recovery. The participants' begin with routine activities which support a move from dependency to independency.

In hospital they have relied on health professionals to assist with personal activities, such as washing and dressing, but now they are home they are keen to resume personal responsibility. Assistance in hospital and the rapid discharge home will have limited their opportunity to independently test their body. As such, they are unprepared and have to quickly appreciate that physical recovery is not as straightforward as simply waiting for the sutures/ clips to be removed and the wound to heal as the following narrative illustrates:

"I think once you are home, you also feel, well I'm home now, I can do that, you know, I don't need help with that. But you also have to know your limitations because I didn't. I went wrong the first week with that. And it was the district nurse, she said I think you should be sitting down a bit more and not keep getting up and going to your kitchen and back and I realised yes, I was doing a bit too much." (8/1)

Expectations and assumptions based on previous patterns of activity are no longer valid and require time to recognise and appreciate. This woman receives guidance from a health professional to legitimise her use of recuperation time. She does not fully appreciate that her wound needs time and rest to heal, which potentially jeopardised aspects of her own recovery. Her previous role as primary carer for her husband is taken for granted and creates a self imposed pressure to resume this role as quickly as possible. Previous activities are a theme in participant narratives:

"I always make an effort and always do and always have done since I retired that I would have one good cooked meal a day." (1/1)

This man talks of an activity which might outwardly appear trivial to others, but is significant to him as this represents a meaningful behaviour which has been

disrupted by the illness. His ability to create a meal may have been assumed in the past but in his current situation, an inability to perform may weaken his self esteem. A degree of independence in activities is a normal adult experience and relying on the assistance of others undermines feelings of control and autonomy. Whilst this reliance is to be expected in the early days at home, most participants' are eager to regain independence. Pacing and introducing small increments in activity levels facilitate progress, as does accommodating depleted energy by incorporating regular rest periods. These strategies promote attainment of a positive outcome which bolsters feelings of control and confidence. This woman clearly describes how she introduces activity in small stages:

"There was one time, I did my exercises and I walked, I had, every day and every afternoon I got a bit further and further and further till eventually I walked to the shop and back". (6/4)

This woman had always been able to walk to the shop and back in the past and her ultimate goal is to regain this independence. Tobin and Begley (2008) describe how patients need to regain a sense of pattern. In a life disrupted by cancer and treatment, asserting control over physical activity is a starting point for repairing the self. Achievement of activity gives impetus to forward development, the "capacity to advance" (Godfrey & Townsend 2008), and is perceived as positive confirmation towards body repair. However, protracted or variable symptoms challenge this perception. Faircloth et al (2004) talk of how an individual may attune to an emerging sense of "becoming old" which gives legitimacy to "slowing down". This approach is suggested in the following quote:

"Not as high in stamina but that may be due to being, how old am I? 69. And I don't feel any different as a person but I don't have the stamina which I did. It is not important, we manage very well." (9/4)

The illness causes this woman to reflect on her past and acknowledge she no longer has the physical durability she had previously. With support from her husband, depleted endurance is not a problem and can be accommodated. This approach requires a change in the meaning of recovery (Godfrey & Townsend 2008) and a modified definition of body repair, as the individual realises that some differences are more permanent. Tiredness and lethargy are features within the narratives of all participants' and represent a serious handicap to six individuals in particular. These six individuals, including the woman above, experience tiredness throughout the twelve months of the data collection. The following excerpt is another example.

"I would just like to know when I am going to get my energy back or if I might get my energy back. It has been a thing all the way through. I have never felt as I did before."
(4/4)

Experiential learning and listening to the body take on increasing importance as the individual assesses their progress of body repair. Tiredness causes frustration and dismay as it negatively impacts on other areas of life. This woman feels uncertain and questions whether her energy levels and physical function will ever be restored to an acceptable level.

Another significant feature of physical repair, evident in all participants' narratives, relates to altered bowel habits, particularly diarrhoea or loose stools (table 10).

Symptom	T1*	T2*	T3*	T4*
Tiredness	1; 2; 3; 4; 6; 8; 9;	2; 4; 6; 8; 9; 11; 12	4; 6; 8; 9; 11; 12	4; 6; 8; 9; 11; 12
Wind	1; 2; 3; 6; 7	2; 6; 7	6; 7	6; 7
Abdominal pain	2;	2; 3; 11	3;	3; 12
Loose stools	1; 2; 3; 4; 5; 6; 7; 8	1; 2; 3; 4; 6; 7; 8	1; 6; 7; 8	1; 6; 7; 8; 12
Constipation		1; 8	1; 8	8
Poor appetite	2; 8	2; 8		

Table 10: Symptoms reported by participants' at data collection intervals

*T1 - 2 weeks post surgery; T2 - 3 months post surgery; T3 - 6 months post surgery; T4 - 12 months post surgery

Altered bowel habits are a feature of experiences leading up to diagnosis and in the post treatment phase, represent an important symptom by which the participant's assess their body repair. Early in the recovery phase, little improvement in altered bowel habits suggests body healing is not yet complete. However, as time passes and bowel function continues to fluctuate, a degree of acceptance can be noted. Twelve months after surgery, this man is not completely certain as to how his bowel habit will be as seen from this quote:

"I mean, it is looser than it used to be but not an inconvenience. That is what [the doctor] said, I said no it is not an inconvenience. I used to go once or twice or perhaps even three times first thing in the morning and that was it. So perhaps that is the way I am going to be now." (12/4)

This man is gaining experience and familiarity over time regarding his pattern of bowel habit. He begins to develop confidence in anticipating the pattern of his bowel

habit which lessens the inconvenience he experiences. Gaining knowledge through experiential learning affords him a sense of predictability and enhances his feelings of control.

Restoring control through resumption of activity is also noticeable with regards to dietary intake. Participants' explore the association between their dietary intake and their bowel habits (see Box 6).

"I don't eat so much wholemeal bread now because if I eat too much wholemeal bread and sort of too many jacket potato and leave the skin on it, I get terrible, terrible stomach ache, really bad stomach ache. Lower down and I can get the most foul wind and I really can't seem to do anything about it. I did see the GP about the wind and she gave me some capsules to take which were peppermint capsules but I can't honestly say it helped that much so I haven't bothered with those. And I won't eat onions, I can't eat baked beans now either because they all have this rather windy effect on me and it's a bit embarrassing when you're out. You've got to escape somewhere quickly and so I tend to keep, I can eat, I don't touch broccoli anymore, well I do but not as much as I used to eat. Broccoli gives me wind as well, I eat spinach, spinach doesn't. Ordinary greens don't, that is fine. If I put garlic in food it can have the same effect. Salads are fine but I don't have any onion at all, no spring onion. Tomatoes, beetroot, lettuce are all O.K. I can eat cheese and eggs. Pasta and rice is fine, I can't eat as much as I used to, that really fills me up."

Box 6: Excerpt from (6/4) illustrating association between dietary intake and bowel habit.

Eating out is an important social activity for many participants', but may have to be curtailed if food is seen to have a detrimental impact on bowel habit. Participants' conduct detailed and lengthy observations of their diet. The consumption of certain foods is noted to induce socially unacceptable behaviours such as passing flatus. This creates emotional distress and embarrassment and the individual is tempted to withdraw from activities and social interactions which previously gave pleasure. The uncontrollable element of dietary behaviour serves to remind individuals of their disease and places them under pressure to restore a sense of control. Experimentation of withholding and introducing specific food products creates a personal list of acceptable foods which do not "upset" the individual. Avoiding these unacceptable foods therefore offers an opportunity for the individual to exert some control over their behaviours which have positive consequences for their meaningful activities.

4.4.1.2 Body monitoring

Body monitoring is a specific action undertaken to assess progress of body repair and resuming activity. Body monitoring requires an awareness of the physical body gained from careful observation. The body is "watched" for a period of time to elicit details of how it is functioning. Specific attention is directed to the experiences and sensations experienced within the physical body as illustrated in the following quote:

"A pain in my stomach which isn't really a pain, it's a sensation which when I bend over or sit down on a chair, in and out of the car, I really get this stabbing feeling."

(9/1)

Paying attention to the physical body and describing sensations can be a new experience. This woman uses a variety of words to describe the same sensation, suggesting she is learning a new language. She appraises the sensation for frequency and intensity, and interprets her experiences in relation to her daily interactions. Certain activities appear to exacerbate her experience and may be detrimental to body repair. As such, she may be able to manipulate her actions to prevent a recurrence of the sensation.

Body monitoring will continue as long as there is a need to observe and assess the body. Additional or new physical changes will cause uncertainty and require ongoing monitoring. Protracted symptoms suggest that the body is not yet healed and requires more time. Three months after surgery, this woman continues to body monitor, trying to make sense of symptoms which cause distress and uncertainty. The sensation in her abdomen has subsided but other symptoms have occurred:

"...this absolute tiredness and it really is a shattering tiredness. I just want to fall asleep all the time and I was always one to sort of, even after the operation, to hop out and go for a walk around the shops, cup of tea out, come back, watch television until about 11 o'clock and then go to bed. I can't keep my eyes open anymore. I sit down after I've been out shopping, we come back in and that's it. I just want to collapse in the chair and I've just got no energy. No energy at all." (9/2)

She describes the tiredness in relation to how much disruption it causes to her activity. Time becomes significant within body monitoring as expectations for repair have to be adjusted. In contrast to her experiences shortly after surgery, the tiredness is now more prevalent and is threatening to overwhelm her. Routine daily tasks are undertaken with great effort and she appears to have little influence over

the experience. She feels uncertain because she now feels how she felt before the operation and is worried this may indicate a recurrence of disease:

"I feel so tired and I really feel like I did before the operation". (9/2)

Most patients will have the greatest improvement in health over the first 12 weeks after surgery (Taylor 2007), however tiredness and fatigue are reported as long term consequences of cancer and treatment (Ulander et al 1997). Variability in the symptom experience creates uncertainty and ambiguity with regards to body repair. The individual will question whether the symptoms are normal and to be expected as a consequence of surgery, or whether they are suggestive of residual/ recurrent disease. Protracted symptoms may lead to a preoccupation with body monitoring as illustrated in this excerpt from a narrative:

*"But then, I think, the problem which I have still got started on December 19th, I've made a note.... it did return somewhere around about early January... So Jan 15th I started making notes ... still slight pain in the evening, good nights sleep. 16th, 4 pm slight tummy ache, sometimes it is tummy ache and then gets down into the groin."
(2/2)*

This man uses skills and knowledge from his previous work as a bio-scientist to understand and makes sense of his symptoms. He writes meticulous notes, recording the date and time the symptom occurs, where the symptom manifests and associated activities. Introspection and interpretation became key features of his descriptions, reflected in his use of scientific language:

"...the last bit of the walk I had groin and tummy ache for 15 minutes. Got into the car, still some slight pain, at home had feet up and snoozed for 15 minutes and the pain went. But then, that is another variable which may not be significant." (2/2)

His behaviour is unusual and he is the only person to spend so much time monitoring and recording his experiences. His example might be viewed as a deviant case however this man experiences a recurrence of disease and he dies shortly after the second interview. His detailed notes are testament to the unrelenting symptoms he experiences as his disease progressed.

4.4.1.3 Comparing

Comparing is linked conceptually with body monitoring, as the processes often occur simultaneously and are inter-dependent. There is a degree of mutuality as heightened body monitoring results in enhanced comparing while the individual attempts to make sense of their body experiences. Comparing is concerned with appraising and assessing whether one experience is similar or of equal quality to another. Changes to the physical body are noted, for example in the following quote the body smells differently following surgery:

"The other variable is that the flatus is very strongly sulphural smelling, more than it was before surgery" (2/1)

Comparing enables the individual to evaluate the relationship between different experiences and provides some form of measurement to observations from body

monitoring. Comparing the present symptom experience to that of the past will indicate whether the symptom is better, worse or the same as before:

"On rare occasions it is diarrhoea but I would say very rare. I would call it a loose bowel motion rather than diarrhoea. There is no urgency around it, thankfully it has always given me time and I have always been at home. I know about diarrhoea from before the operation and I used to think it was the iron tablets I was taking. But nothing like that since." (8/2)

This woman's description shows evidence of her comparing different episodes of the same symptom, to consider whether the consistency or frequency of stool has changed. The current symptom of the "loose bowel motion" is different from the "diarrhoea" she experiences pre surgery. This woman is, therefore, reassured that her symptoms are a consequence of surgery and a normal feature of physical repair. Comparison enables the individual to observe any pattern or predictability to the symptom, offering the possibility of control and mastery in the future. Participants use comparison against their own personal experiences frequently, perhaps because they are isolated from others who have undergone similar treatment. They may also feel socially inhibited from discussing intimate topics, such as bowel behaviour, outside of the medical encounter. Personal experiences can be informative, as one woman discusses:

"The hip operation went beautifully and they let me go home early .... I bounced back from that operation." (4/1)

This woman's previous experience provides confirmation of a successful recovery from surgery in the past. She alludes to an expectation that the current recovery will

follow suit. Previous experiences can inform the present recovery by providing a foundation for interpretation. In contrast, there is the possibility that previous experiences are not appropriate comparators and raise unrealistic expectations for recovery.

Wills (1981) proposes the Downward Comparison Theory, whereby an individual under threat will compare themselves against another who is perceived as less fortunate. An example is noted in this woman's narrative:

"We tend to think oh, we're the lucky ones, there are a lot of people going to be without jobs soon, we try to push on like that." (9/1)

Comparing against someone who is perceived to be in a worse situation can lend reassurance to the individual by strengthening their confidence in the positive aspects of their recovery (Gillies & Johnston 2004). This woman and her husband both have cancer and comparing against others is unlikely to offer reassurance regarding physical repair. Instead, she chooses to compare against the plight of society in general, to an aspect of her life which is settled and predictable. She and her husband are retired and have financial security. Drawing comparisons against the societal aspect of life of work and finance offers momentary relief from the otherwise all consuming impact that cancer is having on her family.

4.4.2 Nurturing

The availability of a nurturing and supportive environment assists the process of recovery. In the first few weeks, attention is given to the home environment. Being comfortable, warm, and safe are important to enable physical recovery. Those who

live with family members are more able to progress through recovery at their own pace. They can take on activities as and when they feel able, because their family will assist. Families nurture by providing time and comfort. They may also assist with aspects of physical recovery, even if not always prepared or knowledgeable about what to do, as in the following example:

"..then he had a little bit of bleeding from the wound and when I looked it was just an open wound and I was horrified, I thought it needed stitching. But apparently not. I didn't know what to really expect you see." (Wife of P7/4)

Recovery is a new experience for the spouse and family. This participant's wife is unprepared: both for the event itself (bleeding) and how to respond. She attempts to attend to the wound, but is distressed because she has not been forewarned of what to expect. Being in receipt of essential information is important as the family rely on this to inform their supportive role, as the husband of participant 8 explains:

"She [doctor] explained how the digestive system works and what each organ contributes and I thought that is the sort of thing I really needed to know and I will have to read it again." (Husband 8/4)

This husband is used to making decisions based on knowledge and is comfortable assuming responsibility for understanding the information relevant to his wife's condition. He perceives this information as vital to enable him to support and nurture his wife during her recovery. He therefore plans to take further action to ensure he understands as much as possible. Nurturing requires emotional and affective support (Pierret 2003) and, when provided by the family, is associated with social wellbeing and patient self efficacy (Arora et al 2007). An individual will grow in confidence as

the family provide background support and encouragement to develop independence. In contrast, those with limited family or support networks are isolated and by necessity, have to regain independence more quickly as is the case for this man:

"It's just me here now and my daughter is really good but she works hard so I just get on myself." (1/4)

This elderly man has been widowed for many years and was completely independent prior to his operation. Disability induced by the surgery, albeit temporary, is difficult for him as he does not want to burden his daughter who will have to take time away from work to care for him. He purposefully keeps his daughter ignorant of his needs and does not seek emotional and physical support from her. As such, he assumes responsibility for his own self reliance. He potentially places himself under added stress at a time where rest and recuperation are essential for the recovery process.

Although only seen in one participant's narrative, the literature testifies to the disharmony that illness can highlight within the family network (Charmaz 1983; see Leahey and Wright 1987). Inability to perform usual functions can undermine an individual's status within the family unit. If the family respond in a negative manner such as failing to acknowledge the individual's needs or by not offering support, then the individual will suffer from growing isolation and self apportioning blame. Charmaz (1983) terms this a discrediting encounter. Earlier in this chapter, excerpts were shown from a man who spent considerable time recording his physical symptoms. He receives limited nurture and support from his wife with regards to his symptoms as suggested by his comments:

"I hadn't said it to her. She says I am always moaning you see." (2/4)

Within his narratives this man describes at length his various roles around the home, including routine tasks such as emptying the dishwasher, gentle housework. He does not adopt a sick role and instead appears to legitimise himself and the roles he is able to perform. He strives to continue despite increasing frailty and regular occurrences of pain which limit his activity. During his interviews, his wife is often present in the background, entering and then leaving the interview space without speaking or interrupting. Tellingly, this man begins a detailed daily recording of his recovery experiences which he shares in detail during the interviews. In response to growing social isolation as his attempts to seek comfort or reassurance from his wife are repeatedly blocked, he uses the interview to unburden his worries and anxieties. In a self depreciating way, he comments *"let's see how I can help you with our study"* (2/3). His wife's behaviour confirms to him that his situation is not worthy of attention; in marked contrast to the time and attention from the researcher. He begins to refer to himself as a co-collaborator within the conduct of the research study, suggested by his use of "our study". Kerns (1995) has suggested that more attention should be directed towards experiences such as these, where family behaviours influence the illness experience for the individual, rather than how illness impacts upon the family unit.

Coping with cancer can either enhance or disrupt normal family relationships (Maughan et al 2002). Relationships can become fragile as family dynamics change through altered function and roles. Another example of how cancer causes strain as previous roles have to be relinquished is seen in this woman's narrative:

"The only thing I do notice is, we both notice it actually, our sons don't seem to come and see us very much since we've both said we've had these problems." (9/4)

This woman spends considerable time reflecting on her family and her children's response to her illness. A previously nurturing relationship within this family, maintained through weekly visits and thrice weekly telephone calls, ends with her announcement of her diagnosis. She is saddened by the loss of support from her family and attributes this to the additional emotional burden induced by her illness. Changes in family dynamics can lead to deeper introspection and threaten feelings of personal esteem. The individual may become more sensitive to the behaviours of others, assuming any changes are a negative reflection of them self, leading to personal blame and self discreditation (Charmaz 1983).

4.4.3 Reclaiming control

The diagnosis of cancer and the disease process itself, along with hospital practices, act as factors to undermine and weaken feelings of personal control. As a result, participants became powerless and dependent upon the health professionals. Once home, the process of repairing the self takes account of these experiences and participants act to reclaim a sense of personal control. Properties of reclaiming control include regaining voice; follow up; information seeking.

4.4.3.1 Regaining voice

Expression of voice is about making personal thoughts, opinions and feelings known, to both the self and to others. Two ladies were offered adjuvant chemotherapy during their first outpatient appointment following surgery, but both refused. The first quote presented here illustrates some of the beliefs which influence this woman's decision:

"I had said that I didn't want chemotherapy. I'd rather die because I've heard how uncomfortable it can be. At my age. For a younger person, I can understand them wanting to and I know many people who've had chemotherapy years ago but it felt right to be saying I'm not going to have it." (8/1)

In an extreme comparison, this woman would prefer death than experience the unpleasant side effects caused by chemotherapy. She has no personal experience on which to base this belief but has heard anecdotally how bad it can be. She experiences significant lethargy following surgery and, as such, has limited personal resources and energy with which to endure further physical hardship. She implies that the potential benefit of added life expectancy is less relevant to her because of her older age. She is confident and comfortable in her expression of voice as this is a true reflection of her views regarding what is important. The doctor requests verification of her decision at the next consultation:

"We chatted through how I was and then he began to elaborate on the fact that I had chosen not to have chemotherapy so he then began to elaborate on cancer, that sometimes it can spread quickly and sometimes it takes a long time." (8/2)

The doctor points out that it might take a long or short time, but there is a sense of inevitability that the cancer will return. He therefore appears to be challenging her decision. The doctor has already ascertained how she is during their "chat", and yet raises the possibility that she might wish to reconsider her decision regarding chemotherapy. She remains resolved that this information will not change her decision: *"It still wouldn't have changed mine." (8/2)*

Taking an active role in decision making regarding treatment options can enhance feelings of self governance and autonomy, particularly if the decision appears to be different from that of the health professional. Once home, multiple factors affect the individual's decision making process and influence their expression of voice. Another example is seen in the following narrative, where this woman refuses chemotherapy because she is the main carer for her husband:

"I refused, well I didn't refuse, I declined the chemo because I discussed it with our own GP and I said apparently it's about 2-3% chance of it happening again, it's a very low percentage and she agreed with me it was a low percentage and really I'm taking more care of [husband] now than I've had to before so I didn't want both of us being ... It really would have been... So I just felt I don't think it's that necessary....." (9/1)

She weighs up the information she has about the risk of disease recurrence and discusses this with her GP. The overriding concern for this woman is to care for her husband and she believes the side effects of chemotherapy would restrict her ability to manage this role. She has limited opportunity to discuss her concerns about chemotherapy with the hospital professionals and instead relies on her GP. However, a later discussion with another GP raises some doubts about the information she has received and how this influences her decision:

"What did come as a bit of a shock and I know this probably sounds silly, well it wasn't a shock but I just thought oh, they never told me that. I was up at the doctors about two weeks ago and he said to me..... well of course, he said, it was a very aggressive tumour and I thought oh, nobody had ever told me that. They just said to me oh it's just a tumour and I expected like other little things I've had removed before now, it was that small. But it wasn't". (9/2)

Her GP informs her that the cancer is an aggressive type. This disclosure of information is unexpected and she has no time to prepare. The validity of her previous decision is in doubt as she had been acting in a context of what she understands to be a "small tumour". Her previous understanding is in jeopardy as she is misinformed. Misinformation adversely affects the expression of voice as any decisions made are not an informed decision. This situation may encourage some individuals to defer to the opinion of the expert as *"they know best"* (12/3). Experiences such as this can reinforce a belief in paternalism; that the individual should hand over all decision making to the professional. Studies indicate that the decision making preferences of patients are variable, with some choosing a very active level of involvement and others preferring a passive response (Beaver et al 2005; Beaver et al 2007). Only two participants were involved in decisions regarding adjuvant treatment, but both clearly demonstrate an expression of voice. One woman remains confident in the decision she made while the other woman has some doubts as further information became available. The issue of information disclosure will be discussed in a later section.

4.4.3.2 Follow up

The schedule for follow up appointments is determined by hospital practice and based on the views of the individual surgeon as evident for participants' in this study. The following data extract illustrates how one woman describes a follow up schedule based upon a biomedical view:

"I went back three days after and then 2 weeks after and they didn't want to see me again after that. There was no cancer so there was no reason to go back." (3/4)

This woman's experiences suggest that the priority for follow up appointments is given to treating the cancer and monitoring for disease recurrence. As the surgeon believes all the disease has been removed, there is no need for her to attend again. Little attention at this time is devoted to aspects of recovery other than the physical removal of disease. Ambiguity is experienced as participants are advised they do not need to be seen and yet are offered further appointments:

"When I last went he said everything is alright, you have no problems anywhere with the cancer now and he said I wouldn't want to see you again. Then again he said, come up in six months just for a check but I know you will be alright when you come."
(1/2)

This man highlights an implication that follow up appointments are simply a formality because the surgeon does not anticipate any further difficulties but still wishes to see him again. This man's expectations for a straightforward recovery have been formed from conversations regarding his cancer and treatment. Also he is aware the cancer has been removed. If experiences at home do not tally with expectations, the individual may experience conflict. They then rely on their own interpretation and makes decisions accordingly, as this woman illustrates:

"Only wind really and painful wind, and some excruciating wind and I was on the point of ringing and I thought no, I'll just leave it a bit longer and it went. I have been on that point on several occasions, perhaps when this is a bit more than just wind." (3/1)

Regular episodes of abdominal discomfort were at odds with this woman's expectations for recovery because the surgeon had informed her: *"I would make a*

quick recovery because it was only keyhole." (3/1). Even when the pain is very severe she feels it is inappropriate to contact the team outside of the prescheduled appointments. Four participants describe situations where they are unable to determine if their concerns are significant enough to warrant contacting someone:

"I've got a check up appointment in January at the hospital ... and I mean if I can hang on till then I would feel happier about it really. I don't want to go up there for no reason at all, I mean the hospital's so busy, you can see it's busy up there." (9/1)

This woman does not want to bother the hospital professionals as she deems her concerns are less important than the needs of others. Uncertainty regarding what action to take can hinder the individual as they begin to reclaim personal authority. Lack of clear information compounds their decision of whether to seek further advice or trust the doctor's reassurance that all will be well. This uncertainty can lead to stagnation, an inability to process information or thoughts. The individual has to adopt their own pattern of behaviour to manage this uncertainty. Initiating contact requires proactive behaviour which is difficult if the individual doubts the validity of their concern because of a lack of experience or knowledge. Asserting personal control will be more complex if the individual feels the hospital team are just going through the motions and that follow up schedules impersonal, as this man experiences:

"We got in there for the meeting and he said oh, you're looking better. A lot better than last time he said. He was confusing [me] with somebody else." (7/4)

This man acknowledges a lack of attention on the part of the doctor who fails to recognise him. This creates a feeling of impersonality and emphasises the routine

bureaucracy within the system. From the outset of the consultation, the health professional makes the assumption that this man is well, based upon his outwardly appearance. This type of blocking behaviour will require the man to be more assertive if the doctor's initial impression is not an accurate reflection of the reality of his recovery. The language used by health professionals also suggests they are less interested in the participants impressions of recovery as illustrated by comments such as *"how well"* someone is looking; you have *"no problems"*; *"I don't want to see you again"*. While the health professional aims to offer reassurance, the participant perceives this as dismissive. Experiences such as these can add to the uncertainty for participants regarding who to contact if they need advice.

4.4.3.3 Information seeking

Prior to discharge, information within the hospital setting was provided at the discretion of the health professional. The majority of this information had a strong biomedical focus on the disease site and planned surgery. Opportunities for further information acquisition were restricted by the short hospital admission, as can be seen in the following quote:

"And more time to ask questions because you get home and you think, oh what did they say about that?" (8/4)

In retrospect, participants feel they have few opportunities to ask questions and there is a lack of time to absorb information. This is a feature common to many narratives regarding experiences within secondary health care services. At discharge, participants are still recovering from the general anaesthetic which adversely affects

their ability to retain information. Information they do recall from discharge is non specific and impersonal (see box 7).

"They just said to take it easy, nothing specific really." (5/1)

"Someone just said to take a couple of painkillers if I needed to." (7/1)

"I didn't have any leaflets or anything when I was discharged home." (10/1)

Box 7: Excerpts from narratives to illustrate discharge information

After discharge, participants are aware they can contact the hospital if they have any concerns, although few do so as explained by this woman:

"And you haven't really got anybody, they give you a telephone number to ring and of course you would ring it but not for such a trivial thing and I waited." (9 /4)

This woman is given a contact telephone number by an anonymous individual within the hospital. The short length of admission and rapid transition through treatment prevent her from getting to know named individuals as care is provided by the team. The cursory manner in which she is given the contact number seems impersonal and inhibits her from making contact. This woman's narratives alludes to the impersonal and anonymous health service through her use of "they"; "nurse"; "anybody" to denote various health professionals. At home she feels isolated and spends time reviewing her questions, deciding they are not important enough to warrant disturbing the team. If she does initiate contact, she does not know who will respond and whether they will know anything about her situation. The importance of being able to access relevant information for the individual is articulated by another participant:

"So I suppose to have reassurance from someone who's been dealing with telling you, that is perhaps more reassuring than going to the GP who's never seen you before and hasn't had anything to do with the operation at all and is just going on the outside symptoms and what they can see on the day." (3/4)

This woman confirms that many information needs are specialised and, as such, not the common domain of the GP. Information needs relate to both the operation itself and also the wider effects of surgery. This woman raises the issue of familiarity with a named health professional, highlighting that a key worker offers reassurance to the individual that attention will be given to their personal circumstances. Participants' identify similar topics as areas of unmet need, often relating to the impact of physical symptoms upon activities of daily life, as summarised by this woman:

"That is one of the things I would have liked some advice on and nobody ever really said. Some sort of diet information, even if it was just a sheet of what you should and shouldn't have. It would have been very useful." (3/2)

Information and advice regarding diet and tiredness are the most commonly mentioned topics of unmet need. Participants want information about how to manage these symptoms and lessen the impact on daily activities. Research has highlighted fatigue and lethargy as post operative complications experienced by colorectal cancer patients (Dunn et al 2006). Another area where participants often want information to provide reassurance relates to what constitutes a normal pattern of recovery. The same woman describes how her lack of experience and information creates uncertainty:

"It has all been such a new experience it is hard to say what you should have done or how you should have felt or I should have just dismissed those pains as things healing themselves. You just don't know. The whole thing is so new, you haven't been through it before and you just don't quite know which way to go, you don't want to bother people stupidly, you don't want to waste people's time because it is just something that is going to happen or should you leave it and it is something serious and you should have gone. It's very difficult. I hate going to be looked at, I hate going to the doctor and I hate feeling I am wasting their time but at the same time you know, I left it before when perhaps I should have been more demanding and you know, you don't quite know which way to go sometimes." (3/3)

She describes a process of inner turmoil and uncertainty about how to act, where to seek advice, how to access information. Knowing who to contact is difficult as this woman is unclear who has medical authority for her. Seeking advice for a range of recovery needs is also complicated if participants' believe the hospital professionals primary focus is on disease status. Participants' consistently report uncertainty regarding the legitimacy of their information needs, citing busy health professionals as an inhibitor to seeking advice. Past experiences of the time surrounding diagnosis come to the forefront for this woman as she recognises she is repeating past behaviours with her reluctance to seek advice. Her past behaviours are significant as they delayed her time of diagnosis and she now wonders if she should be acting more promptly in her recovery. These conflicting thoughts can create burden and strain on the individual, weakening feelings of confidence and control at a time when they need to assume more personal responsibility.

4.4.4 Accommodating the cancer

Accommodating the cancer involves acknowledging the losses induced by the cancer diagnosis and treatment. These losses may be physical, such as loss of a segment of the bowel, or they may be losses affecting the self like the loss of control or choice. In the early weeks of recovery, the individual focuses on physical losses. Appreciation of the loss of internal organs is postponed as external indicators of the surgery are hidden behind dressings as described by this woman:

"I know it still has to heal internally even though there is no visible signs, hasn't it? I don't know how long it takes to heal internally. You have to think there is something there that has been done." (11/2)

Dressings obscure the reality and external appearance of what has been done. This woman is unable to use sight as a primary sense to comprehend what has happened. This loss of a primary protection mechanism can heighten feelings of vulnerability. As dressings are removed, the small residual scars appear relatively innocuous and time is needed to appreciate the discrepancy between external appearances and the internal loss. This discrepancy is also apparent in the responses of others as this woman explains:

"Nobody believed I had anything wrong with me. Quite disappointing sometimes. I couldn't act the, you know, the poor little invalid." (4/3)

Others perceive this woman as well and she has no outward indicators that mark her as a cancer patient who has had surgery. She chooses to see humour in this situation, but may be at risk of over burdening herself in the early days of recovery if her losses are difficult to demonstrate to others.

Other significant loss is felt in the domains which provide meaning and pleasure in life. Examples include relationships and activities which give purpose to life as described next:

"I never ever thought that would happen to me and I'd planned my life with all these bloomin' horses that I was going to breed and do things with and now I think I can't do that, I really can't. Just in case." (3/4)

For this woman, the cancer is a source of major disruption to her present life and also to her future. She had planned for a future where she was in control of aspects of her life that were important. Now, ambitions have to be shelved as the cancer has shown how unpredictable life can be and the future will always be uncertain. Taylor (1989) has also commented on the loss of hope for a future as the individual loses belief in a benevolent world.

An unpredictable future threatens personal control as the individual cannot anticipate or plan for what will happen. An individual may adjust behaviours to enhance control and the possibility of a healthy future, for example adapting diet:

"I mainly drink green tea now. Things like that. I am a bit careful about what I eat and drink. It is a change and I probably don't drink as much rubbish like fizzy drinks. I just feel I've got to look after myself a bit better, don't you think?" (11/4)

This woman associates certain foods with a healthy lifestyle and deliberately chooses to omit products which she perceives as unhealthy. Her experience of cancer, which she may link with dietary intake as a causative factor, has prompted her to review

other aspects of her behaviour which may influence her health in the future. Consideration of causative factors for cancer is also mentioned by one man:

"They reckon it is too much red meat and not enough exercise. Everything is bad for you." (12/4)

This man suggests there are many possible causative factors for colorectal cancer. Some potential causes are under the control of the individual, and others are not. For some individuals, seeking a cause for the cancer can aid understanding of how an event occurred and contribute to a sense of control.

4.5 Summary of repairing the self

The process of *Repairing the Self* begins from the point of discharge from hospital. In the first few weeks at home, *Repairing the Self* is primarily focused upon the process of physical healing. For some participants', physical repair takes longer and may leave residual problems including tiredness and altered bowel habits. Over time, the participants' also address the emotional and social impact of the cancer diagnosis and treatment. Regaining a sense of control and self determination requires time and the opportunity for reflection. Participants' may rely on their friends and family to provide a nurturing and supportive environment during this time. Support is available from hospital health professionals but the routes of communication are not easily accessed by participants. Participants' are reluctant to initiate contact as they perceive that their needs are not of significance.

4.6 Phase three - restoring the self

Restoring the self is the final phase of the recovery experience. Participants' describe this phase as an enduring process in relation to two perspectives: a sense of wellness, or a sense of illness (figure 3). One perspective usually takes precedence, however, participants' can oscillate between the two perspectives or demonstrate aspects of both perspectives simultaneously. The participants' expectations, beliefs and perceptions regarding their recovery will influence which perspective takes precedence. The definition of a successful recovery is perceived as variable and fluid, in response to intrapersonal and interpersonal interactions over time. The participants' experiences are influenced by the interplay between their mind, body and emotion, in addition to the context of their wider social environment. As such, the narratives and data analysis have conceptual links to the Shifting Perspectives Model of Chronic Illness (Paterson 2001). The Shifting Perspectives Model describes how living with an illness is an ongoing process where illness and wellness co-exist. The reality of the illness experience and the individual's personal social context will influence whether a sense of wellness or illness is in the foreground.

4.6.1 A sense of illness

A sense of illness is noted for participants' who focus upon the sickness and burden caused by their disease. Some participants' experience this sense of illness as a transient episode; for example in response to a reoccurrence of a symptom, or when they have contact with health services. For others, a sense of illness is an overwhelming and all absorbing experience which preoccupies much of their emotional and physical energy. A sense of illness is demonstrated in the narratives

Figure 3: Restoring the Self: a Sense of Wellness, a Sense of Illness

in relation to three categories: unresolving symptoms; threat of cancer; struggling with temporality.

4.6.1.1 Unresolving symptoms

One man has a strong sense of illness as he experiences a recurrence of his disease and dies four months after surgery. Leading up to the time of his recurrence, he is engrossed with his daily symptom experience which he records in a diary. A woman also describes a preoccupation with her cancer diagnosis and the ongoing limitations imposed by her illness experience. Throughout the twelve months of data collection, this woman experiences a multitude of physical symptoms which reoccur and then dissipate. The symptoms vary in intensity, duration and magnitude and defy all her attempts to exert some control over their manifestation. As such, she feels a lack of confidence and becomes preoccupied with habitual body monitoring and comparing as demonstrated in the following quote:

"Experimentation. See if anything works and some things did and some things didn't. Sometimes I thought it did and then it didn't. It is something I am constantly thinking about it now which I must admit I didn't before. I am constantly thinking about, well should I eat that? Is it going to give me tummy ache in the night?" (3/4)

Twelve months after surgery this woman continues with her dietary modifications. She experiences abdominal discomfort which often develops into significant pain, most commonly during the night. She associates the pain with her dietary intake and defines her attempts to modify her diet as experimental, suggesting she is continually trying new measures as nothing has been proven effective yet. Commonly, any small measure of success in alleviating the pain is short lived as she will then experience a

relapse of the symptom. Her failure to break the cycle of dietary intake and nocturnal pain creates feelings of despondency and emphasises her lack of control. Eating is a regular activity and she is forced to spend personal resources of time and energy on studying this aspect of her daily life. Her symptom experience continues to have a significant and protracted impact upon her daily life and forces her to maintain a sense of illness.

This woman is not the only participant to have symptoms one year after surgery although her situation is the most extreme. Several participants continue to experience lethargy which they describe as being *"tired a lot of the time"* (11/4), or *"just feel sort of weak all over really."* (12/4). One woman describes her experiences at twelve months post surgery:

"I keep thinking I ought to, because that operation was so fantastic, it was all over and I was so up and leaping about afterwards as if I had had nothing wrong with me but I do suffer from lack of energy." (4/4)

This woman refers back to her past. She developed an expectation for a quick and straightforward recovery as the surgery has been efficient and minimally invasive. She was out of bed within a few hours of surgery and discharged home promptly. Her early impressions of recovery were that physical recovery should be quick and complete. Over time however, she is commenting that her feelings of lethargy limit her ability to engage in meaningful activity. Her experiences do not tally with her expectations and she is required to spend time considering her situation. Consequently she feels frustration as she is forced to dwell on her illness, placing her in the perspective of a sense of illness.

4.6.1.2 Threat of cancer

The woman who associates dietary intake with her nocturnal pain explains how the physical symptoms she experiences raise fears of disease recurrence:

"I must admit I keep going back to that conversation and keep hanging on to that conversation. They have cured me because they have given me another 20 or 30 years of life and whatever niggles and pains, it can't be that, it must be just the settling down so I did hang on to that conversation whenever I felt worried. But at the same time when you've got quite a bit of pain going on you can't help but think oh perhaps they were wrong. Nobody is infallible. You can never be 100% sure that things have been, so perhaps something has happened, perhaps they are, perhaps it hasn't worked as everyone expected." (3/4)

This woman explains how her symptom experience impacts upon her emotional health and forces her to adopt a sense of illness. From her past experience, the symptom of pain is an indication that something is amiss. The persistent symptoms bring the diagnosis to the forefront of her mind, and create feelings of omnipresence (Shaha & Cox 2003). She attempts to counteract the fear by focusing on the information she has been given by the hospital team. However, she struggles to believe this information as her symptoms continue unabated. Thus her symptom of pain is the focus of attention which, in turn, impacts upon her psychosocial health, creating fear and vulnerability which perpetuates a sense of illness.

4.6.1.3 Struggling with temporality

Another manner in which participants' demonstrate a sense of illness relates to their conception and articulation of time. Participants' who have a sense of illness often

describe the passage of time in relation to the treatment calendar (Schou & Hewison 1999). This man makes frequent reference to his recovery as measured through the treatment calendar:

"Well he said to just come and see him for a check up in 3 months" (1/1);

"He said to come see him in six months, just for a check-up" (1/2);

"He wants to see me after one year, just to check up on me" (1/3);

"He said we've already booked you for another twelve months" (1/4).

This participant is one of the few to have frequent outpatient appointments following surgery. By allocating time to attend these appointments, other aspects of his life have to be adjusted. This participant's family live abroad and he visited them every year prior to his illness. As he recovers, he decides that the schedule of his outpatient appointments takes precedence and he therefore postpones his visit. His attitude that regular monitoring is necessary is encouraged by a health care system which books future appointments before his attendance at clinic. Health care practices foster attention to the treatment calendar, reinforced as participants' anticipate future investigations and repeat colonoscopies. This regular attendance at hospital can lead to participants' dwelling on a sense of illness as it serves as a regular reminder of their cancer.

As the first year anniversary of surgery approaches, this woman comments on the significance of time in relation to her disease:

"When it was recently done [surgery] and I was told I was cured and everything like that, you tend to believe it totally and you are absolutely fine, oh great, that is gone, it is finished, it is gone, all behind me. And now sort of nearly getting on a year later,

and you do hear stories of people where it has happened again, and you think a year has gone by and if anything is going to happen it might happen in the next few months. So yes, I think I probably think about it more now than when I first came out of hospital to be honest." (3/3)

Approaching this one year anniversary provides a focal point for her anxiety. Information she has received from health professionals after surgery becomes less believable over time, particularly when at odds with her daily experiences. Following surgery she believed that her illness episode was complete and in the past. However, twelve months later her ongoing symptom experience leaves her unconvinced that her disease has been cured. Her experiences force her to remain in the present, engrossed in how her symptoms are influencing her life. Future time is anticipated with fear as she believes any recurrence of her illness will manifest in the near future. For this woman, a sense of illness is a prominent feature of her recovery as time is measured in relation to her disease status.

4.6.2 A sense of wellness

In contrast, a sense of wellness is demonstrated through an awareness and enjoyment of the emotional, spiritual and social aspects of life. The physical body is just one facet of the self and is not the centre of overwhelming attention. Participants' will experience varying degrees of a sense of wellness. Often the participant will be required to direct attention and energy to actions which encourage a sense of wellness, for example, participating in meaningful activity to restore a sense of fulfilment and enjoyment. Restoring a sense of wellness may require the participant to identify and access resources to resolve or accommodate the challenges

presented by their illness experience. Characteristics of a sense of wellness include: confidence in the body; mapping the future; appreciating life; mobilising resources.

4.6.2.1 Confidence in the body

As they approach twelve months after surgery, participants with a sense of wellness demonstrate increasing appreciation and knowledge of their body as described in this quote:

"Physically I have picked up very well. I have bounced back very quickly. I was in a car accident many years ago and remember when I recovered from that. The more you do, the quicker you recover. So I deliberately keep moving. I didn't want to overdo it but I would do some jobs in the house or the garden, then have a rest, and then do some more. I went back to work part time. I told the head of department what I had had done and he was very understanding." (10/4)

This man describes his physical recovery as an ongoing process where the past and present are interwoven. Experiential learning from a previous illness episode has been used to inform his present recovery. From past experience he believes that constant physical activity will aid the process of healing. This knowledge underpins his actions and he demonstrates body listening skills and introspection to inform his decisions. He is confident in his knowledge of his body, illustrated by his ability to predict how his body may react when he returns to work. In anticipation of this, he negotiates a reduction in his working hours to continue his progress of physical recovery. Confidence in the body is not simply related to physical efficiency, but instead implies a sense of knowing and familiarity which creates confidence to

anticipate and predict. One woman describes how her body is not as efficient as in the past but she is attuned to the physical sensations of her body:

"If I feel tired in the afternoon now I have a nap and that three quarters of an hour makes me feel much better. I am not pushing myself as much now, taking life easier. You get so used to pottering around, going off here and going off there and, it isn't so much that you're enjoying life, it's not that, it's that you're used to doing these things and so now I don't do as much as I used to. That's it really." (9/4)

This woman continues to experience tiredness twelve months after surgery and this tiredness has to be accommodated. She has gained confidence and familiarity with her body and can adjust her daily routines accordingly. She uses reflection and introspection to interpret her experiences as she acknowledges that in the past she would have engaged in activities because they were routine and habitual, rather than because they gave pleasure. Participants' with a sense of wellness do not necessarily have complete restoration of physical health but they do have confidence in their ability to predict or control their physical body. These participants' demonstrate this confidence by engaging in meaningful activities. They will view failure to progress in the activity as a positive opportunity to moderate or vary the activity. Expertise is demonstrated when the individual uses this new knowledge to adopt strategies to minimise or avoid risk activities in the future.

4.6.2.2 Mapping the future

Participants' who express a sense of wellness view the passage of time in relation to their personal calendar. They are not consumed by a timescale dictated by the

treatment calendar. Reaching the first year post surgery is an important milestone and is viewed as a positive achievement as this woman comments:

"It's gone very quickly the last year. I feel pretty well, no complaints. It's gone very quickly, lets hope the next four years goes as well." (11/4)

Participants' who have a sense of wellness will view the first year anniversary as confirmation that recovery is progressing well. This woman remains mindful of the treatment calendar which measures recovery in terms of five year survival, but does not dwell on this. A man also comments on the five year timescale, using humour to lessen the significance of this timescale in relation to his disease:

"I've got to wait five years and then I can have a party. So he said. I think they check you for about five years. Just to make sure that everything is O.K. I don't worry at all before I go for the outpatients." (7/4)

This man acknowledges the five year survival date is one adopted by the health professionals, but it has less relevance to him. His attendance at hospital does not cause him to dwell on his illness and he maintains a sense of wellness. His attention is devoted to his long term plans to renovate the family house. This has long been an ambition for him and is an activity which gives him enjoyment. His plans for the future are therefore determined by personal ambitions and goals, with little reference to the cancer. Participants' who develop a sense of wellness increasingly describe their recovery and the passage of time in relation to their personal or social calendar as illustrated by this woman:

"We had been talking about it for a while and just decided that it would be a good time now to do these things, we want to get a little flat somewhere where we can, and as soon as the market gets better I think probably that is what we hope to do." (9/3)

This woman talks of plans she and her husband had discussed in the past, and which were now being brought forward to action. Her decision making is influenced by her illness experience in that she wants to move somewhere smaller to reduce her physical burden. However, her decision is also influenced by external factors of the current socio-political environment. She sees a future where she makes a fuller realisation of her personal ambitions and goals. Participants' with a sense of wellness no longer have to live from day to day, controlled by their illness experience. As Charmaz comments (1997:190), mapping a future involves expanding one's time perspective. A sense of wellness enables the participants' to act as and when they choose. They are not restricted in time by their illness and the illness is predominantly viewed as a past event.

4.6.2.3   Appreciating life

Participants' expressing a sense of wellness have a sense of acceptance of how things are, and of normality. They may adjust their expectations of normality, perhaps by modifying their activity levels or adjusting certain aspects of their diet, but these modifications are not viewed as disruptive. These participants' may also express a heightened sense of being alive, and an appreciation of the present and future by acknowledging the past and what they could have lost as illustrated by this man:

"I make the most of my life while I've got it. I reflect that this time now might not have been mine. I could have been decaying. When you really consider that you might not have a life, you come back and get on with your life. It's made me spend more time with the family and doing things I want to do. In the past I always did what I had to, what I thought I had to do." (10/4)

This man has a renewed appreciation of life in response to his illness experience. He spends time reflecting on the past and that he is fortunate to have the opportunity for a future: "I could have been decaying". He perceives his future as an opportunity for further personal growth and time to participate in meaningful activities, rather than simply just passing through life. Before his illness, his future life would have been one of routine and obligation. For this man, his sense of wellness is perhaps more profound than before his illness episode, evident in his determination to make the most of this future he now has, for however long it may last. As described by Moch (1998), this man views his illness experience as an opportunity to increase the meaningfulness of his life through his connectedness with his environment and his awareness of self. Surviving cancer has provided him with an opportunity and gives legitimacy to instigate changes to his life. As Rasmussen and Elverdam (2007: 620) suggest, the loss of future time is turned into time that is gained and "a gift of life".

Participants with a sense of wellness acknowledge their diagnosis of cancer but are able to put the cancer diagnosis into the background. This man explains how he draws on his previous experiences of coping:

"I know I've had cancer, I've got cancer but you just have to get on with life. I have always been like that. I don't sort of worry about health matters as such." (7/4)

This man demonstrates the ambivalence he feels regarding his cancer diagnosis. He has cancer and yet is able to move forward in his life. Part of this process involves an appraisal of the risk of disease recurrence and the individual has to decide how to manage the emotions that may result. The emotional impact of the cancer diagnosis can be significant as this woman explains:

"You keep quite a bit to yourself but it's not really a physical thing with me, I think it was more mental, sort of, it would go away, but you couldn't really forget it, sometimes people would say oh, forget it and it will go away but I couldn't really forget it, no. I think when somebody says to you, cancer, I've learnt in the last year, so many people have cancer that whereas it used to be a horrible big word that came to your mind and you felt horrified, I don't feel like that anymore about, I really don't."
(11/4)

This woman describes how in the early months of recovery she had a stronger sense of illness as she was unable to "forget" her cancer. She dwelt on her diagnosis which was never far from her conscious thoughts. As time passes, she learns that cancer is prevalent and is a common feature of life which reassures her she is not alone. In response she is able to develop a stronger sense of wellness as she learns to accommodate and manage her emotional fears induced by the cancer diagnosis.

4.6.2.4 Mobilising resources

Mobilising resources is a phrase coined by Bury (1982) and is evident in the narratives of participants who express a sense of wellness. Participants' rely on a variety of resources, including personal attributes and characteristics, in addition to

other resources which are found within their social environment. This man has a good social network of neighbours who provide him with support as he describes:

"I have my brother up at [town], they come down. My neighbours, I have got some good neighbours, anything I want, they used to look in before when I had the wife and if I ever wanted anything you know. It is a good area. I have some good neighbours here." (1/4)

Based on his past experiences of caring for his disabled wife, this man knows his neighbours will help him if required. This knowledge reassures him and gives him confidence that he is well supported. As such, he has a sense of wellness in that he feels secure with his familiar and available sources of support.

Four participants talk of the supportive relationship they have with their GP. This woman explains how her relationship with her GP has developed over time:

"He is also the doctor for the nursing home so that was useful. He came in two or three times. I was there almost three weeks. He came in then and it was good, it was very, very useful. He has been my doctor for 14 years. Yes, he's always been helpful. Not over the top but I depend, trust him." (9/4)

This woman's GP recommended she have a short convalescence in a nursing home following her operation. Whilst in the nursing home she appreciates the continuity of contact with this familiar health professional during her early weeks of recovery. The length of their relationship has enabled her to build a sense of trust and dependency. Consequently she feels able to rely on this GP if she has additional support needs once she is home.

Interestingly, no participants' accessed support groups, either in person or via the internet. Two participants' commented they would seek advice or support from the hospital team if required. Instead, the majority preferred to rely on their friends and family for physical and emotional support if they needed to, as this lady discusses:

"Well they are just too busy aren't they really, I wouldn't think, I can always talk to my daughters if I need to. I've got lots of good friends I can talk to if I need to, but I don't really need to." (5/4)

This woman views the health professionals as too busy to be a valuable source of support for her. Instead she prefers to focus on her family and friends. In her sense of wellness, she does not perceive that she has support needs at present but has the reassurance of friends and family if required.

4.7 Summary of chapter

This chapter has presented the grounded theory *Restoring the Self: a sense of wellness*. The grounded theory has three phases: Disrupting the self; Repairing the self; and Restoring the self. Excerpts from the participant narratives have been used to illustrate how the analysis is grounded in the data and how the theory has emerged. *Restoring the self* is an enduring process in relation to two perspectives: a sense of wellness, or a sense of illness. One perspective usually takes precedence, although participants can oscillate between the two or demonstrates aspects of both perspectives simultaneously. A successful recovery is perceived as variable in response to social interactions and where a sense of wellness pervades.

CHAPTER 5: DISCUSSION

5.1: Introduction

This chapter discusses the results of the study with reference to the key themes emerging from the data analysis. The themes are discussed in detail and in relation to existing knowledge. In accordance with grounded theory and discussed in chapter 3, the main literature review has been conducted after the core category emerged. The literature is referenced throughout the discussion chapter, to illustrate how the grounded theory links to, and expands upon existing knowledge.

5.2 Original research question

This study aimed to develop a grounded theory which explains the process of recovery after completion of surgery for colorectal cancer. Research questions included what is the process of recovery when cancer is experienced as an acute illness, with rapid diagnosis and treatment, and a short hospital admission? The study considered participant's experiences over a one year period, when they had limited contact with health professionals after completion of treatment? Participant behaviours with regards to health information provision were explored. Grounded theory emerges from the data and the data cannot, and should not be forced to fit what the researcher hopes to find (Glaser 1992; Strauss & Corbin 1990; 1998). Through inductive data analysis, a grounded theory has emerged which describes the experience of recovery as a return to a sense of wellness. Cancer causes disruption to the individual's physical integrity through the manifestation of symptoms. Hospital practices and medical interventions disrupt personal identity by threatening

personal control and autonomy. Following surgery and discharge home, participants respond to these disruptions by taking actions to restore physical integrity and personal identity. Recovery is experienced as promoting a sense of wellness which enables the continuation of a personal biography. Accessibility and utilisation of information resources are interwoven throughout the participant's experiences of recovery. At times, information behaviours are overt, at others more covert and not acknowledged or recognised by the individual. Accordingly, information issues are discussed throughout the chapter and specific recommendations for clinical practice are identified.

5.3 *Cancer as an acute or chronic illness?*

Participants in this study describe characteristics of an acute illness. Several have a sudden and acute onset of symptoms and are rapidly referred to specialist services. Investigations and treatment involve multiple specialists; a short hospital admission for specialist surgery; a rapid discharge home and an expectation of a straightforward recovery. Rier (2000) characterises critical illness by an acute and rapid onset; a sense of the immediacy and focus on the present; and the compression of an individual's social horizon to the acute treatment setting. As such, participant's experiences within secondary health services and the receipt of medical care are characteristic of an acute illness episode. The sociological study of illness has paid little attention to acute or critical illness (Lawton 2003; Rier 2000).

In contrast, sociological research has focused upon chronic illness (Pierret 2003). This is because chronic illness is prevalent, chronic illness is perceived as more disruptive to the individual, with longer lasting consequences; and dissatisfaction with the Parsonian paradigm of illness associated with acute illness (Rosenfeld 2006).

Whilst cancer may be compared to chronic illness due to improved survival rates and people living with and beyond cancer (Corner 2008; Little et al 2000), there are fundamental differences between cancer and chronic illness (Tritter & Calnan 2002). Cancer includes a range of diseases, with distinctive incidence, mortality and treatment; and some are potentially curable. The complexity of cancer necessitates multi-professional input, with intense and acute episodes of treatment, alternating with prolonged periods of chronic management. Cancer is associated with mortality (Shaha & Cox 2003), and those newly diagnosed with cancer will feel they have been given a death sentence (Corner 2008). In contrast, chronic illness emerges over time and diagnosis rarely leads to a rapid referral for specialist treatment (Bury 1982; Pound et al 1998). Chronic illness typically manifests as a series of stages; at times improving and at times getting worse (Newbould et al 2006).

Participant's experiences of recovery have conceptual links with chronic illness (Bury 1982; Mathieson & Stam 1995), and the illness experience (Paterson 2001; Tobin & Begley 1988). Participants describe how cancer disrupts their previously familiar and taken for granted life (see Bury 1982) and threatens their sense of personal identity (see Mathieson & Stam 1995). Recovery is experienced through developing a sense of wellness, with illness gradually being pushed into the background (see Paterson 2001). This chapter includes the conceptual vocabulary of chronic illness throughout and draws upon seminal work including chronic illness as biographical disruption (Bury 1982), renegotiation of identity proposed by Mathieson and Stam (1995), and the shifting perspective model of chronic illness (Paterson 2001). The medical management of colorectal cancer may be defined as an acute illness, but the social context and cultural meanings imbued by cancer create an illness experience beyond the immediacy of curative surgery.

5.4 *Disrupting the self*

At first interview (within one month of surgery), participants were asked to describe what had happened. They begin with descriptions of themselves and their lives prior to diagnosis. They describe their personal identity in terms of physical health and function, lifestyle and roles they had before the cancer diagnosis. For some, their personal identity was stable with good health, ability to perform in roles including work and participate in activities. Other participants describe good health, but having co-morbidities which require attention and influence normal routines. Authors have noted that research participants often begin their stories with descriptors of the time before diagnosis (Godfrey & Townsend 2008; Pound et al 1998). Participant's distinction between time before and after their diagnosis of cancer, suggests a demarcation of time, supporting Bury's (1982) contention that illness is a disruptive event. Making reference to their life before illness may be one way participants attempt to incorporate their diagnosis into their life biography, to create a sense of continuity between the past and the present. This would confirm Williams (1984) suggestion that stories begin in the before time to place the illness in the context of the present. This may also reflect the newness of their experiences, or illustrate their hopes for the future and a return to this former identity.

5.4.1. Body disruption - the early recognition of change

A strong theme in the analysis relates to the recognition and interpretation of symptoms in the pre diagnosis phase. Most participants experience an insidious and diffuse onset of symptoms which are unacknowledged for a time. Participants report with hindsight that they fail to recognise warning signs that something is amiss. Some remain unaware of symptoms until these are diagnosed incidentally by their GP. These findings are comparable with characteristics of chronic illness reported in

the literature (Broughton et al 2004; Molassiotis et al 2009; Sanders et al 2002). Many participants have existing co-morbid diseases, which masks new symptoms or provides a rational explanation for deteriorating or changing health. The gradual onset of symptoms and their ambiguous nature, leads participants to adopt a "proximal kind" of explanation (Bury 1982) where symptoms are normalised by attributing to a less serious origin (Lugton 1997; Smith et al 2005). Examples are noted where one woman associates symptoms with the menopause, another with irritable bowel syndrome (IBS). Co-morbidity is common in advancing age and may already have caused significant impact upon the health of the individual (Faircloth et al 2004; Ogle et al 2000). Age is evident in the data as a factor which normalises aspects of the symptom experience. Participants attribute increasing tiredness and lethargy to advancing age although younger patients (under 65) attribute these symptoms to overwork. Associating symptoms with advancing age and therefore acceptable as a natural and inevitable part of life, is confirmed by Pound et al (1998) and described by Sanders et al (2002) as the "natural degenerative theory".

Recognising symptoms of colorectal cancer is complex because symptoms are invisible or hidden. Changes to the body occur internally and the resulting bleeding or looseness of stool appears "behind" the body, hidden from view unless the individual specifically chooses to observe. Internal symptoms can often be attributed to other health conditions, for example Goff (2000) identifies that women diagnosed with ovarian cancer initially associate symptoms with menopause, increasing age, and life stress. A lack of outwardly visible symptoms can delay recognition of abnormality. Arndt (2002) observes that finding a breast lump is a trigger for 96% of women to consult their GP within one month and Ramirez (1999) finds that a non-lump symptom is a risk factor for delayed presentation.

Shortening delays in the presentation and diagnosis of cancer forms a substantial component of national strategy within the UK (DoH 2004a; 2006) with the purpose of reducing cancer morbidity and mortality (DoH 2000b). Symptom appraisal delay is significant and can account for delay in presenting for medical advice in 60%-70% of patients (Andersen & Cacioppo 1995). A lack of knowledge regarding symptoms is apparent for participants in this study because when they do recognise symptoms, they are quick to seek medical advice. The literature attests to poor levels of knowledge regarding colorectal cancer (Adlard & Hume 2003; Nichols et al 1996); associated with lower education, socioeconomic status and being male (Brunswick et al 2001; Evans et al 2005; Ristvedt & Trinkaus 2008). Participants in this study are of higher education and socioeconomic status, which suggests public awareness campaigns such as colorectal cancer awareness month are required. Participants are unable to ignore symptoms when they become burdensome and interfere with daily activities. Disruption of normal roles forces participants to recognise symptoms and acknowledge ill health as reported in the chronic illness literature (Bury 1982; Corbin 2003). This creates a re-awakening of the fallibility of their body, bringing the normally absent body into consciousness (Leder 1990). This renewed awareness of the body can present a focal point marking the transition from health to illness (Mathieson & Stam 1995; Tobin & Begley 2008).

5.4.2 Access and treatment within secondary care services

A high proportion of participants in this study (n=7) were referred to specialist services by their GP according to referral guidelines colloquially known as the 2 week rule (DH 2000a; 2006). These referral guidelines have had mixed results regarding early presentation to specialist services (Allgar & Neal 2005; Mitchell et al 2008), with a minority of patients referred via this pathway (Barrett et al 2006; Masson et al 2007)

and no evidence of shortened diagnostic pathways (Neal et al 2007), or shortened delay in time to treatment (Flashman et al 2004).

Participant's experiences within secondary care are of a rapid treatment pathway, with little time between referral, investigations and surgery. The rapidity of the treatment pathway highlights the seriousness of a potential cancer diagnosis. Participants are reassured by the rapid transition as they received prompt attention, and yet they experience heightened fear as they have no time to reflect or assess their situation. This ambivalence between fear and reassurance with rapid treatment pathways has also been described by men having surgery for penile cancer (Bullen et al 2010). Anxiety and distress may be further heightened if individuals are ill prepared and uninformed (Lovgren et al 2010). The rapid treatment pathway creates a dependency upon the health professionals to navigate the treatment pathway and keep participants informed. Participants give few examples of involvement in decision making and instead appeared to acquiesce as a necessary consequence of receiving prompt treatment for their cancer. Radley (1999) describes how illness causes the immediate mobilisation of medical treatment, creating the ultimate displacement of the familiar everyday world. This loss of control over time management and personal choice is alien to many and fosters dependency and powerlessness (Hummel 2009). For participants, dependency is fostered by the acute and intense nature of medical interventions; but may be more acceptable due to the relatively short duration of contact with secondary health services.

Participants describe a health service with a strong biomedical identity. Interactions with health professionals are dominated by medical content, in part determined by the necessity of rapid treatment. Frank (1995) describes a shift in the cultural context in which people now experience illness, a time he labels "post-modern". This post-

modern experience of illness is characterised by technical expertise, evinced by the health professional within a complex organisation. Participants in this study revere the medical expertise of the surgeon and talk of having trust and faith in the medical team. They accept the need to hand over responsibility for their treatment to the medical experts. Delegating responsibility for managing one's illness is articulated by Parsons in his work "the sick role" (Parsons 1951). Within this theory, being ill is seen as an undesirable state and socially regulated to minimise disruption to the individual's life. The ill person is not culpable for their illness but is responsible for seeking help from an institutional health agency (Bury 2000). Becoming a patient is a new experience for some participants and they typically adopted a passive approach by handing over responsibility and decisions about their care to the professional. The French philosopher Foucault argues that institutional power is intrinsically linked with knowledge and is about ways of making people, by them self, behave in ways they would otherwise not have done (Foucault 1977). Evidence of this argument is seen in the deferential response of participants to the cultural prescriptive behaviour of the health professionals. Medical training and historical practice encourages the doctor to adopt a hierarchical position within the medical consultation (Clark & Mishler 1992) while cultural pressure fosters the portrayal of expertise and authority. Foucault claims a belief system (such as the institution and medicine) gains momentum (and hence power) as more people come to accept the views associated with that belief system as *common knowledge* (Foucault 1963; 1977). Participants in this study are clustered in the age range 65-87 years and, therefore, grew up in an era of cultural belief in medical authority and the beneficence of medicine. The individual is deferent to the professional who holds authority and power. Whilst a loss of personal autonomy is usually perceived as negative, Williams and Koocher (1998) discuss how temporarily relinquishing control to the health professional during a period of acute illness may be beneficial as it enables access to expert treatment.

Participants describe the language and nomenclature spoken by health professionals which serves to emphasise a biomedical view of their illness experience. Unfamiliar medical language and histology results are often heard during the disclosure of their diagnosis and, whilst participants were able to recall some details, most struggled to understand the terminology. Instead they focus upon a positive reassurance that their cancer is small and insignificant. Radley (1999) talks of doctor talk, where the doctor is approaching the interaction from a differing "plane of experience". Medical details and truths are the only valid form of address (Mathieson & Stam 1995). Professionalism is seen as truth: the factual truth of medical science; the beneficent truth of institutionalised health care; and the political truth of managing people's welfare (Frank 1995). The dichotomy between familiar and everyday language used by participants, and the professional language used by the doctor can result in a lack of comprehension or misunderstanding. This situation is seen for participant 9 where she has not appreciated the significance of her diagnosis with regards to adjuvant chemotherapy. Chapman et al (2003) suggest misunderstanding of terminology used during cancer diagnosis disclosure is common. Lobb et al (1999) found that women did not understand the terms relating to survival and relative risk associated with or without adjuvant treatments for breast cancer.

Rodriguez et al (2008) propose that general and indirect language may be used in consultations when discussing poor prognosis or negative outcomes. This may serve to buffer the patient from the emotional impact of the information. Another possibility is that health professionals use what Habermas (1991) calls "distorted communication" as a strategy for purposive action. This purposive action directs attention towards the medical aspects of the consultation and deflects the disclosure of personal and subjective communication. Enabling participants to disclose personal

matters is unpredictable and less familiar to a surgeon who is experienced and versed in managing medical truths, facts and highly specialised technology. The rapid nature of the treatment pathway for participants is an obstacle which restricts time to discuss anything other than procedural issues. The emphasis on the urgency of the diagnosis directs attention to medical aspects of management and leaves little opportunity for the participant to raise other subjective or personal concerns. Barry et al (2001) discuss the "voice of medicine" and the "voice of lifeworld" (patient focused communication). They found increased use of the "voice of lifeworld" has better outcomes and more humane treatment of patients as unique human beings. However, best outcomes are noted in consultations where both the doctor and patient are using the same communication pattern, which in some situations may be the "voice of medicine".

5.4.3 Emotional disruption

Participants describe a variety of emotional responses to receiving their diagnosis. Attending hospital for investigations creates anticipatory fear and anxiety even before receiving a confirmed diagnosis. Tobin and Begley (2008: 35) describe this anticipatory uncertainty as "suspected-knowing", a time of suspicion, of "knowing and yet not". This marks the point at which the individual moves from the "everydayness life" to life lived, the "before and after" of the cancer diagnosis. Emotions at this time varied from a stoical acceptance, to feelings of complete shock and being unprepared for such news. Some feel overwhelmed by the diagnosis and struggle to comprehend the information. Thoughts of mortality have not always been considered by participants, particularly those who are younger. Little et al (1998) comment that illness renders visible some things that were transparent before the illness or diagnosis. Fear is mentioned by participants and is heightened in those with

personal experiences, or knowledge of someone who has died from cancer.

Participants use personal knowledge as a reference frame against which to consider their own diagnosis. This knowing provided the backdrop for their anxiety (Tobin & Begley 2008).

A small number of participants initially express denial or avoidance behaviours. They have not wanted to know any further details of their cancer, preferring to focus on treatment. Telford et al (2006) discusses acceptance and denial as descriptors of the response to chronic illness. These descriptors may simply become labels for behaviour which is seen as maladaptive, rather than considering an individual's subjective response. In accordance with Saegrov and Halding (2004), participants do not receive time or opportunity to talk about the emotional impact of the diagnosis. Provision of emotional support may lessen feelings of fear and helplessness (Mathieson & Stam 1995), particularly during waiting times between investigations and confirmation of diagnosis (Schou & Hewison 1999).

5.5 *Repairing the self*

In response to the disruption caused by the illness and treatment, the individual will enter a phase of repair, with the purpose of restoring personal identity. Personal identity becomes what it is through the body, and is the self's representation in the world (Corbin 2003). Therefore, the immediacy of physical repair is the priority for the first weeks at home.

Participants experience varying degrees of body failure in response to physical symptoms, surgery and medical interventions. The loss of control of the body is unfamiliar to some and creates concern and anxiety, as found by MacDonald (1988).

The desire for the return of a familiar body becomes a deliberate endeavour early in recovery (Taylor et al 2010). Rest and recuperation become the mainstay of recovery in the first few days, as the individual has limited stamina and strength due to protracted illness prior to diagnosis. The rapid discharge within 24 hours of surgery also leads to acute exacerbation of weakness from surgery, with some feeling residual effects from anaesthesia.

Bodily repair has to be attended to as it limits or interferes with other physical and social activities (Kelly & Field 1996). Participants engage in body monitoring and comparing to evaluate physical recovery. Family members and primary care professionals provide an external source of monitoring. Several research studies have highlighted how symptoms may continue for months and even several years after surgery for colorectal cancer (Arndt et al 2006; Macvean et al 2007). Achieving control over physical symptoms and the body is important for several reasons. Firstly, physical suffering will lead to emotional suffering because the self is affected by what happens to the body (Corbin 2003). Secondly, failure to control the body causes uncertainty and a sense of unpredictability. Participants are unable to plan or take purposeful action in this context of unpredictability. Heightened anxiety is experienced as a lack of consistency in the symptom experience creates ambiguity with regards to the meaning of the symptoms (Galloway & Graydon 1996). For a small number of participants, ongoing symptoms experiences raise fears of disease recurrence. A common strategy adopted by participants is temporal comparison where an individual compares their current status with previous or anticipated status (Suls & Mullen 1983), and this has been demonstrated in other studies (Dowswell et al 2002; Godfrey & Townsend 2008). Suls et al (1991) found that a group of older persons use past and future temporal comparison to evaluate perceptions of health; and this is significantly correlated with a lower self rating of health. For the older

person, present health status may be worse than past health and is likely to deteriorate in the future. This creates an interesting question regarding participants as, despite advancing age, they might anticipate an improvement in their future health following the removal of the cancer and physical repair. Comparing against others is a pervasive social behaviour (Suls et al 2002) and appears frequently in health literature (Pound et al 1998; Sanders et al 2002). Taylor and Lobel (1989) describe how patients with cancer may prefer to compare "down" to others less well off than themselves, to gain reassurance that they are in a superior position. However, they prefer to be in contact with those are better off i.e. upward comparison, to gain a role model or recovery pattern to aspire to. The inherent danger in using post temporal comparison is the setting of unrealistic expectations for the recovery phase. Participants assume that recovery will follow previous experiences, creating disappointment when this is not achieved. Many talk of "back to normal", implying a strong sense of temporal comparison. Downward comparison is used occasionally, often to anecdotal reports within the community rather than a specific example (Suls et al 2002). This may also reflect a lack of suitable comparables as recovery took place in isolation.

5.5.1 Protracted symptoms

Participants in this study describe physical symptoms as consequences of cancer and treatment. Fatigue and altered bowel habits are an enduring feature of recovery for many participants and have a detrimental effect upon their daily lives. Studies of recovery commonly rely on quality of life measures to assess sequelae of treatment (Armes et al 2009), including physical and functional ability; emotional and psychological wellbeing, family and social aspects; and estimates of overall quality of life (Anthony et al 2001; Zebrack 2000). Physical symptoms are associated with a

decrease in functional recovery (Hodgson & Given 2004; Ramsey et al 2002). In turn, reduced functional recovery can lead to poorer quality of life as the individual is restricted in performing various functions of daily life (Schag et al 1994). The impact of cancer and treatment has been demonstrated to lower quality of life, in both the short and longer term (Bertero 2002; Kessler 2002).

5.5.1.1 Fatigue

Nine participants experience tiredness or fatigue at some time during the twelve months of the study. Six participants describe fatigue as a significant symptom which persists throughout the study period. Fatigue has been identified as a significant problem within cancer patient populations (Schag et al 1994; Stone et al 2000), for patients upon completion of chemotherapy or radiotherapy (Richardson & Ream 1996; Smets et al 1998), and in colorectal cancer patient populations (Dunn et al 2006; Galloway & Graydon 1996). Fatigue is the medical term for the symptom described by participants as an overwhelming sense of weakness, no energy, loss of strength, tiredness. Ream and Richardson propose a definition as follows:

"Fatigue as a subjective, unpleasant symptom which incorporates total body feelings ranging from tiredness to exhaustion creating an unrelenting overall condition which interferes with individuals' ability to function to their normal capacity"

(Ream & Richardson 1996:527).

Two participants report tiredness in their first interview but this resolves three months after surgery. Kirshbaum (2010) distinguishes between tiredness and fatigue, in that fatigue cannot be relieved easily by addressing deficiencies in sleep or nutritional intake. The literature debates two theories regarding the aetiology of fatigue: one

based upon a physiological response to surgery; the second based upon a cognitive and emotional response (Rubin et al 2004). Some argue that post operative fatigue is related to the degree of surgical trauma but not the duration of general anaesthesia and surgery (Christensen & Kehlet 1993). It could therefore be anticipated that participants in this study undergoing minimally invasive surgery, but longer duration under anaesthesia, will have low levels of fatigue post surgery which would dissipate quickly. However, the number of participants citing fatigue as a distressing symptom suggests a more complex and psychological response. Salmon and Hall (1997) propose a theory in which postoperative fatigue is the product of physiological, psychological and cultural factors. Participants describe their experience of fatigue in subjective terms with regards to daily activity. Fatigue is associated with the curtailment of activity, reduced feelings of control, and a sense of illness. For six participants (one participant died), fatigue continues as an unrelenting problem, remaining unresolved at twelve months. For these participants, fatigue overshadows aspects of their daily life, by restricting the type of activity they are able to perform, or limiting the duration and enjoyment of activities. The enduring nature of fatigue as experienced by these six participants is also evidenced in the literature (Ramsey et al 2002; Ulander et al 1997). Fatigue is a challenge to effectiveness; to an ability to perform activities with ease or spontaneity (Leidy & Haase 1999). One participant describes her escalating fatigue during the data collection period, suggesting an incremental component to the fatigue experience. As healing takes place and symptoms resolve, the individual wishes to increase activity level. Fatigue may then present an obstacle to resuming activity, becoming a more prominent feature of recovery, requiring attention and conscious thought. New meanings are attributed to fatigue as the impact is felt within other domains of personal integrity.

In the immediate post operative phase, most participants adhere to the principles of rest and light exercise. Changes in activity levels may have a psychosomatic component, either through a cultural approach to rest and recuperation; or to avoid exacerbating symptoms such as discomfort and pain. One man does not perceive of tiredness as an issue and instead adopts a stoical attitude where tiredness is a normal experience post surgery. Rubin et al (2004) suggest pre operative expectations for fatigue or a negative mood after surgery, are strongly related to increased fatigue in the first three months following surgery. Therefore it could be assumed a more accepting or positive attitude, as demonstrated by this man, could have a positive impact upon the experience of fatigue.

5.5.1.2 Altered bowel habits and diet

Altered bowel habits, including loose stools, diarrhoea and flatus, are another physical symptom reported by participants. In the first few months of recovery, participants often have unpredictable bowel actions with a tendency towards diarrhoea or loose stools. These unpredictable symptoms cause a degree of uncertainty and emphasise a loss of control, as also noted by Galloway and Gradon (1996). Over time, as participants become more confident in monitoring their bowel activity, they begin to develop a sense of awareness and predictability about their bowel habits. Participants who perceive diarrhoea as a problem adopt self care strategies in an attempt to manage or control their bowel activity. These strategies focus on dietary monitoring and modification to ascertain an association between food produces and symptoms. Dietary modification is also a strategy reported by Pan et al (2010). Participants believe high fibre foods are culpable in causing diarrhoea or flatus and so these foods are avoided. Smaller meal portions and eating at regular intervals are other strategies tried by participants, also reported in the

literature (Campbell et al 2001; Kidd et al 2008). Strategies reported in the literature but not evident for participants in this study include the use of nutritional supplements (Campbell et al 2001; Kidd et al 2008); and the use of anti-motility drugs (Nikoletti et al 2008).

Bowel problems have been reported in nearly three quarters of patients undergoing surgery for colorectal cancer, up to 2 years post surgery (Nikoletti et al 2008). In some cases diarrhoea has persisted for up to five years post treatment (Arndt et al 2008; Ramsey et al 2002). Altered bowel habits therefore represent a significant symptom for some patients. Rozmovitz and Ziebland (2004b) found the negative impact of altered bowel habits created a loss of social confidence for the future, resulting in what they term "social death" (also see Lawton 1998). Participants in this study rely on common sense and personal experience to monitor and manage their altered bowel habits. They comment they would have found dietary advice helpful. Only one man receives written dietary advice. Much of the literature attests to dietary intake for individuals with ulcerative colitis or Chron's colitis (Bingham et al 1982), which may not always be directly transferrable to the individual with colorectal cancer. Other research considers the role of dietary intake in relation to cancer occurrence and reoccurrence (Kuhn et al 2005). Studies show that dietary information is often not discussed, either in hospital or post discharge (Dunn et al 2005; Henderson & Phillips 1996).

5.5.1.3 Issues of self management

What is clear from participants' descriptions of protracted symptoms is that conventional health practice offers limited information and support for self management. Instead, the participants have to develop their own strategies.

Newbould et al (2006) comment that self management is not a new concept as models of coping with adversity based upon self help and self reliance have been common since Victorian Britain. Participants rarely seek advice and when one woman does, the health professional dismissed her fatigue as a symptom of older age. Health professionals may underestimate either the prevalence or the impact of physical symptoms (Volgelzang 1997). Kozachik and Bandeen-Roche (2008) question whether cancer and treatment related symptoms in older people are sufficiently managed. Participant's experiences in this study would suggest that on occasion, their needs are dismissed as a normative experience of ageing and therefore not addressed. This finding is also supported by Pound et al (1998). As Kralik et al (2004) deduce from interviews with individuals with rheumatoid arthritis, self management is a dynamic, active process where the individual learns, trials, and explores the boundaries caused by their illness. For participants in this study, self management becomes a focus for time and energy to review, reflect, monitor, and experiment with various actions. Participants aim to restore a sense of normality to their everyday lives. Regaining a sense of independence, or at least predictability, about their physical function restores a sense of control over their health and wellbeing. Limitations of the physical body can have negative consequences on personal identity because identity is represented and enacted through the physical body (Gillies & Johnston 2004). Adapting to changes in physical functioning therefore facilitates the individual to restore a sense of wellness. In terms of self help strategies, participants who are able to accommodate their symptoms by modifying activities have a greater sense of wellness.

5.5.2 Follow up

The structure of follow-up appointments is variable and appears to be determined by the individual surgeon rather than hospital policy. Participants are not always certain how frequently they will have a follow up appointment or if and when further investigations will be required. Two participants talk of five years of ongoing surveillance to detect recurrent disease and several are aware they will require repeat colonoscopy's at some time in the future. However, they have varying understanding as to the rationale and purpose of follow up attendance. They experience ambiguity when the hospital professionals tell them they do not need to be seen again and yet continue to arrange a further appointment. This ambiguity with relation to the frequency and purpose of follow up is evident in the literature. Surgical follow up adheres to a biomedical model where the primary purpose is to improve survival by detecting recurrent disease (Cardella et al 2008). Common practice within the UK involves three-monthly appointments for two years, and then annually (Papagrigoriadis 2006). However, there is disagreement on many elements of follow up guidelines between international societies (see Li Destri et al 2006). Some studies have failed to confirm early detection of recurrence through follow up (Renehan et al 2002), whereas other studies have shown that intensive follow up has a positive impact on increased survival, albeit costly (Li Destri et al 2006; Renehan et al 2004). Participants are keen to have regular follow up appointments and one man requests another appointment when the surgeon said he no longer needed to be seen. Several participants associate follow up appointments with ongoing surveillance of their disease, to ensure they remain disease free. Fear of recurrence remains a significant and overwhelming concern for one participant in particular. Stark et al (2004) comment that anxiety levels may increase despite reassurance from the doctor, if that reassurance does not address the focus of the anxiety. As time passes, participants put their fear of recurrence into the background until the

next outpatient appointment approaches. Kew et al (2009) comment that women with gynaecological cancer rank detection of recurrence as the most important reason for attending for follow up. Mellon et al (2006) found that fear of recurrence is more strongly influenced by psychosocial aspects, such as family stressors and less positive meanings of illness, rather than the type and stage of cancer. This would support the need for a wider remit for follow up consultations where fear of recurrence is addressed in more complex ways than simply disease staging. With regards to their own needs, participants allude to various reasons for wanting to attend follow up in which detection of recurrent disease is not always the most pressing. Instead, and in the absence of other sources of information or support, they have wider needs including psychosocial concerns and questions about physical symptoms. Participants who have protracted symptoms attempt to discuss these within the follow up appointment. However, several reiterate their concerns throughout the 12 months of data collection, suggesting they have not received information or reassurance. Research indicates that it is not the length of time in consultation, but rather the quality of that consultation which is significant with regards to patient satisfaction (Druss & Mechanic 2003; Ogden et al 2004). Ryan et al (2003) identify that patients with arthritis view the medical consultation as a significant medium through which to retain feelings of control. The consultation is seen as an opportunity to share experiences with an expert who, in turn, offers support and reassurance regarding the patient's experiences. Donovan and Blake (2000) found that, irrespective of the content and language of the consultation, patients are not reassured unless they perceive the doctor listens and responds to their concerns. Participants frequently allude to psychosocial concerns, for example, protracted physical symptoms and the implication for managing activities of daily living. Rozmovits et al (2004a) comment that patients find it difficult to regain confidence when their post surgery symptoms resemble those experienced pre

diagnosis. Follow up appointments could, therefore, provide a forum for the participant to discuss their fears in detail and gain reassurance from the health professional with expertise.

Negative aspects to regular follow up include the reinforcing of what Little et al (1998) call the persisting sense of cancer patientness. Patients do report increased anxiety prior to attendance for follow up (Kew et al 2009; Papagrigoriadis & Heyman 2003), although this is not seen as a barrier to presenting for follow up (Cardella et al 2008). Stiggelbout et al (1997) and Papagrigoriadis and Heyman (2003) comment that patients want to know about recurrent disease even if there is no survival benefit. A small number of participants talk of the anxiety they felt in the lead up to the next appointment. More anxiety is experienced prior to repeat colonoscopy's, although this is related to the discomfort experienced during the procedure rather than a fear of what might be found.

5.5.3 Resuming normal roles

As physical health improves, participants resume daily activities. To assist in progressing with body healing, personal resources are mobilised and "the individual is inevitably drawn into rearranging his or her wider personal and community involvements" (Bury 1982: 175). Physical reliance on others is often an unfamiliar experience and many wish to return to independence as soon as feasible. Activities fall into two broad areas: normal daily tasks; and the resumption of fulfilling, pleasurable activity which promote wellbeing and enjoyment. The first area enables participants to resume normal roles within their social world. The latter enables a sense of personal identity to be reformed and restored. Enthusiasm to restore independence may lead the individual to manipulate their environment (Williams &

Koocher 1998), for example by moderating diet, lifestyle, or seeking information. Many participants moderate their lifestyle and diet in an effort to control symptoms, thereby enhancing daily activities. These behaviours have a dual purpose: to restore a sense of personal control; and to confirm success in recovery through attainment of positive outcomes. Achievement of goals requires attention to the body, re-learning how it responds and then testing the body through purposeful actions, with the ultimate aim of restoring embodied control (Taylor et al 2010). Goals and activities direct attention forward to the future, providing a sense of continuity and consistency between the past, present and future. Bozinovski (2000) suggests continuity is a motivating factor to inform human strategy and is also a continuous life goal. Achieving goals enables a transformation from disempowerment to empowerment as the individual begins to consider what is desired and what is possible. Tobin and Begley (2008) term this a "visible occupancy", the representation of true self characterised by a sense of achievement and personal contribution. Personal identity is strengthened as trust, confidence and optimism for a future develops.

5.6 *Restoring a sense of wellness*

Participants describe recovery as a process of restoring a sense of wellness. A sense of wellness is demonstrated through an awareness and enjoyment of the physical, emotional, spiritual and social aspects of life. Having a sense of wellness exists as a duality with a sense of illness, with movement between the two perspectives. This duality of perspective is discussed by Doyle (2008), who comments on positive aspects of survivorship including feelings of self improvement, personal growth and an appreciation of life. In contrast, survivorship can present negative consequences with ongoing physical symptoms resulting from treatment and adverse emotions such as depression. Participants who restore a sense of

wellness experience more positive aspects of recovery and either have less, or are more able to manage negative consequences.

Survivorship as a concept has evolved to reflect scientific, social and cultural change (Leigh 2001) and is no longer simply defined in terms of disease free intervals. Survivorship is viewed as a dynamic continuum from diagnosis until death (Feuerstein 2007). The literature on survivorship has conceptual similarities to restoring a sense of wellness. Little et al (1998) describe cancer survivorship as a state of liminality; a space between two places. Survivors pass through the space of illness but do not return to the normal world because this world is no longer the same as it was before the illness (Little et al 2000). This sense of transition is evident for participants who moved through a stage of acute illness, and returned home as an individual recovering from colorectal cancer. Their life at home is different as a consequence of their illness. The diagnosis of cancer challenges prior plans for the future, which have to be temporarily halted, modified or discarded. The transitory nature of life leads them to question their beliefs and attitudes towards life (Shaha & Cox 2003). In restoring a sense of wellness, participants adapt expectations and behaviours to their new life situation. Focusing on the future provides forward movement, and restores a sense of purpose and meaning to life. Their sense of arrested temporality experienced at the point of diagnosis does not last and plans for the future began to re-merge (Breaden 1997). Little et al (2000) call this reorientation, where the individual comes to terms with the illness by understanding the limitations imposed and reconstructs their life to give meaning beyond the facts of the illness. Restoring a sense of wellness involves participants assessing and accepting limitations within recovery. This is noted with regards to fatigue as some participants become adept at assessing and monitoring their fatigue levels. They appreciate factors which exacerbated their fatigue, and strategies which enabled

them to manage fatigue to continue with desirable activities. Having less complex expectations for recovery may also be beneficial as those with a "take for granted attitude" have a smoother recover (Winterling et al 2009). Studies suggest that between 20 and 30% of survivors have ongoing health problems, resulting in substantial negative social and economic effects on individuals (Corner 2008). Restoring a sense of wellness includes an element of hope: participants are optimistic that symptoms will subside, or that they will gain confidence and mastery in managing the symptoms. Ramfelt et al (2002) suggest a sense of hope offers some protection against despair. The experience of survivorship is one that deals with "the body as a house of suspicion" (Breaden 1997). Participants work to put symptoms into perspective and categorise tiredness or pain as side effects of surgery, rather than an indicator of disease recurrence. Some participants struggle to view symptoms as nonthreatening and thus retain a sense of illness in the foreground.

5.7 Summary of chapter

This chapter has discussed the results of this study with reference to the key themes emerging from the data analysis. The results suggest that recovery is experienced as a process of restoring a sense of wellness, which has conceptual links to existing knowledge of chronic illness as biographical disruption (Bury 1982), renegotiation of identity (Mathieson & Stam 1995) and the shifting perspective model of chronic illness (Paterson 2001).

CHAPTER 6: CONCLUSION

This chapter concludes the thesis and presents a summary of the study findings. This study adopted a grounded theory approach to explore the individual's experience of recovery following surgery for colorectal cancer. Whilst this study was concerned specifically with colorectal cancer patients, the key themes and implications for practice may have broader implications for patients with other diagnoses. This chapter will also explore the strengths and limitations of the study and propose suggestions for further research.

6.1 Summary of existing knowledge

Colorectal cancer represents a significant disease burden worldwide, and is the third most prevalent cancer in the UK (CRUK 2010a online). Surgery is the definitive treatment for early stage disease (Leslie & Steele 2002). Much of the existing research has adopted a biomedical framework to assess recovery in regards to sequelae of treatment and quality of life scores. Symptoms of pain, insomnia and fatigue are common and may persist for many months following surgery. Studies of patient experiences have suggested the cancer diagnosis and treatment can cause a loss of control and create a sense of uncertainty. In response to physical symptoms an individual may withdraw from their social group, creating social isolation. Less attention has been given to the subjective and emotional aspects of recovery following surgery. Little attention has been given to the individual's experiences over time as they manage their recovery at home and in relative isolation from health professionals.

6.2 Summary of the findings of this study

Recovery following surgery for colorectal cancer is described in three phases: disrupting the self; repairing the self; restoring the self. Disrupting the self is a phase where the cancer diagnosis and treatment disrupt the individual's sense of personal identity. In response, the individual enters a phase of repairing the self where they engage in actions and interactions, with the purpose of repairing personal identity and physical integrity. The final phase of restoring the self revolves around the core category of *Restoring a sense of wellness*. *Restoring a sense of wellness* is fostered through an awareness and enjoyment of the physical, emotional, spiritual and social aspects of life. A sense of wellness exists as a duality with a sense of illness, where both perspectives may co-exist but one usually takes precedence. A feeling of illness pervades when the individual is preoccupied with the illness which continues to disrupt their daily life.

6.3 What this study adds to existing knowledge

This study illustrates how social and cultural meanings associated with colorectal cancer create an illness episode beyond the immediacy of curative surgery. The individual will experience and interpret their illness in relation to their sense of personal identity. Interactions with health services and health professionals can threaten the individual's sense of personal identity, as can the disease process itself. Recovery is more than simply a process of physical repair. The longitudinal approach within this study has enabled exploration of how the individual's experiences and meanings can change over time. This has illustrated that recovery is an enduring and evolving experience.

6.4 Limitations of the study and recommendations for future research

This study recruited a small sample from one geographical location and treatment centre within the UK. The grounded theory may therefore reflect the experiences of this specific population. It is feasible that experiences would be different in alternative treatment centres, or other geographical and socioeconomic locations.

Over half of patients (n=8) had surgery performed by a surgeon who specialised in laparoscopic surgical techniques. Consequently these patients had a shorter hospital stay post surgery (between 24 and 48 hours) than the remaining four participants (average 3 days). This was not anticipated as a potential factor that may influence the recovery experience at the outset of the study. However, data analysis has shown that the length of hospital admission may influence information provision and recall. Therefore, this warrants further attention in future studies.

This study included one individual who required a permanent stoma formation. This man's experiences were not noticeably different and the grounded theory was evidenced in his narratives. Further research is advisable however, to test the relevancy and application of the theory to those who have permanent external physical changes to their body as a result of treatment. This group may have varying experiences with regards to disruption to their personal identity, either from permanent physical disruption or threats to their self image.

The individuals within this study were selected because they did not have adjuvant chemotherapy or radiotherapy following surgical treatment, to enable exploration of how recovery was experienced when there was little contact with health

professionals. The strength of the grounded theory are the implications arising for clinical practice, which suggest that *Restoring a sense of wellness* can be used as a framework for nursing assessment and intervention. This has application to individuals receiving multiple or different therapies, for example, regular attendance for chemotherapy may provide continuity and opportunity for the health professional to incorporate the grounded theory into their regular assessment and provision of care.

To summarise, future studies should:

- consider how type of surgery and hospital length of admission may influence the provision, understanding and recall of information provision.
- include individuals who require a permanent stoma formation.
- Consider the applicability of the grounded theory *Restoring a sense of wellness* to a broader patient group, for example those receiving differing treatment modalities.

6.5 Critique of the grounded theory: *Restoring a sense of wellness*

This study aimed to generate a substantive theory to focus upon the process of recovery following surgery for colorectal cancer. This grounded theory is underpinned by symbolic interactionism, and aims to explain the behaviours and actions within the topic area of recovery. The theory has aimed to develop a mid-range perspective which generalises beyond the individual experience, but considers local systems and context. This grounded theory represents the perceptions and analysis of one researcher and attempts have been made to enhance the credibility of the theory by providing a clear audit trail and description of the analytical process.

In addition, all stages of the study have been conducted and monitored within the supervision process but the theory requires further development and refinement by others. A grounded theory cannot be reproduced as the social phenomena and setting cannot be replicated (Strauss & Corbin 1998). However, this substantive theory aims to generalize the process of recovery, and predict patterns in behaviour (Glaser 1992). These patterns and processes within recovery require further exploration within other population groups. The generalisability of this theory is tentatively supported by the links between the theory and existing conceptual literature of biographical disruption and identity work. I have aimed to develop a theory which is understandable to health professionals and those from a sociology background, although I am mindful that I have conducted the analysis, developed concepts and hypotheses from my stance as a nurse. The merit of a substantive theory is to "speak specifically for the populations from which it was derived and to apply back to them" (Strauss & Corbin 1998: 267). Critique from my health professional and sociological peers will add to the merit of the theory.

6.6 *Key themes for clinical practice*

The following section will briefly summarise the key themes arising from this study with regards to clinical practice. The discussion will highlight issues arising from the analysis, which could provide topics of interest to be addressed within clinical practice and in future research. The purpose of this section is to offer suggestions to improve the experience of recovery for the individual, within the context of modern health services.

6.6.1 Key findings

The key findings from this study are summarised and include:

- The acute experience of colorectal cancer presents a significant threat to personal integrity and disruption to the life biography.
- The individual is at risk of loss of control and personal autonomy within secondary health care services due to the rapid treatment pathway.
- A rapid discharge from hospital limits the opportunity for disclosure of information to the individual in order to assist them in their process of recovery. As such, the individual is vulnerable and has to rely on personal knowledge and experience to inform and direct their recovery.
- Follow up is predominantly structured around a biomedical model where priority is directed to detection of disease recurrence. Less attention is devoted to wider aspects of recovery and, in particular, psychosocial issues and protracted symptoms which hinder resumption of activity.
- The individual may feel isolated within their recovery experience as they have limited resources to provide advice and reassurance. They will often rely on personal knowledge and "trial and error" to inform their recovery in preference to proactively seeking information from a health professional.

6.6.2 Recommendations for clinical practice in the pre diagnostic phase

The time leading up to surgery is a period of uncertainty and anxiety for the individual as they have to simultaneously manage rapidly ensuing investigations, whilst considering the likelihood of a diagnosis of cancer. There is a clear need for information and support during this uncertain time, particularly as decisions may have to be made regarding treatment. Information provision prepares the individual for forthcoming treatment, increases adherence to therapy, facilitates coping with the

illness, and promotes recovery (McPherson et al 2001; van der Meulen et al 2008). However 40-80% of medical information verbally provided by health professionals is promptly forgotten by patients (Kessels 2003). Several factors adversely affect the amount of information that an individual receives, comprehends and retains. For participants in this study, the emotions and anxiety resulting from investigations into possible cancer may have had a significant impact. Ley (1979) discusses how primary focus is given to stress provoking messages such as bad news, to the exclusion of other information. Participants talk of strong emotions and fear at hearing the diagnosis of cancer which is suggested as factors negatively affecting information recall (Siminoff et al 2000). Diagnostic information may also be perceived as of higher importance (Kessels 2003) and therefore less attention is given to other aspects of information. Older age influences the amount of information an individual can understand and recall (Jansen et al 2008) as age related cognitive changes may impede information processing and recall while memory fades more rapidly (Kessels 2003). Another influential factor is the environment and manner in which information is imparted. Modern health services based around rapid treatment pathways and short hospital admissions limit the availability of time and opportunity for information disclosure. Attending to privacy, protected time, and the full attention of the doctor have been identified as very important contextual factors relating to satisfaction with information provision (Buckman 1992; Parker et al 2001).

It is therefore recommended that health professionals are mindful of these multiple factors which influence the process of information disclosure. Health professionals will have to actively promote and provide resources of time and space throughout the pre diagnostic phase. This is especially pertinent during the multiple investigations which are required pre operatively, most of which require separate outpatient visits. During hospital visits, patients will see different professionals who have varying

remits with regard to information provision. A common issue for information provision within busy acute hospital settings is the lack of continuity between sources of information, potentially leading to omission of important facts, contradictory or redundant information (McPherson et al 2001). "Structural holes" as described by Miller and Wadsworth (2009) create gaps where tasks do not get done because it is tacitly understood that they are no-one's individual responsibility. An agreed protocol within and between teams will therefore enhance consistency and prevent ambiguity regarding responsibility for providing information throughout the treatment pathway. The multidisciplinary team meeting provides a forum where specialist doctors, nurses, oncologists, radiologists and histopathologists meet to discuss diagnostic tests and treatment plans (Blazeby et al 2006) and could, therefore, serve as a forum to clarify responsibility for information disclosure.

Each individual will have personal preferences for the amount and type of information they wish to receive (Leydon et al 2000). Ideally, the individual's preferences will be assessed by the health professional but the rapidity of treatment pathways will restrict the time available. Health professionals are cited as the most commonly available information source (Mills & Davidson 2002) and, in particular, the medical consultant (Rutten et al 2005). Rutten et al (2005) also found that patients relied heavily on printed information in the diagnosis and treatment phase. This suggests that health professionals could concentrate on providing essential verbal information, supplemented with written information. Written information leaflets can provide an effective method of empowering patients in understanding and remembering medical information (Dixon-Woods 2001). Written information could include all investigative tests providing clear descriptions of purpose, what is entailed, and what is likely to be experienced. Leaflets should include instructions of where and how to seek further advice or information if required, including a nominated contact. Various methods of

giving information have been researched, including audiovisual aids, audiotapes and patient copies of medical letters (McPherson et al 2001). The evidence remains ambiguous, but suggests that information which is personalised and provided according to the individual's preferences, is most likely to have a positive impact upon comprehension and recall (Johnson & Sandford 2005; McPherson et al 2001; van der Meulen et al 2008).

Summary of recommendations

- Health professionals should actively promote and provide resources of time for information disclosure throughout the pre diagnosis phase.
- Protocols should be agreed between hospital teams to enhance consistency and prevent ambiguity regarding information provision.
- Written information leaflets should include the purpose of investigative tests, listing what is involved and likely to be experienced.
- Leaflets should include details of where and how to seek further advice and information.

6.6.3 Recommendations for information at the time of discharge

Participants receive little information immediately prior to discharge home. Most participants in this study had laparoscopic surgery which requires a longer surgical technique than conventional open surgery, but leads to a quicker discharge home (Lezoche et al 2002). Participants therefore had a longer duration under anaesthesia and a short time to recover before discharge. The increasing demand for short hospital admissions restricts time for patient education (Jacobs 2000) and potentially creates greater information needs due to less contact with health professionals in the hospital setting. Participants receive information pre operatively regarding diagnosis

and medical procedures but receive little preparation for recovery at home. Henderson and Phillips (1996) observe that patients receive technical information but no information about the management of activities at home. Information needs in the early weeks at home relate to basic physical functions including pain control, wound healing, suture removal and activity levels. These topics are cited as the most pressing information needs for patients post surgery (Bradshaw et al 1999), as physical consequences of surgery have an immediate impact in the early days (Galloway & Graydon 1996). Information delivery is crucial to enable patients to plan for, and cope with their postoperative course (de Jesus et al 2006). It is therefore recommended that participants are provided with written information regarding common symptoms and experiences following surgery, in addition to a summary of the treatment they have received. This information should include instructions of how to monitor pain and wound healing at home, what are indicators of normal and abnormal healing, and what actions to take if the individual is concerned. Guidelines for activity should include what activities require moderation and for how long. Participants should be given information regarding bowel activity, advising that altered and unpredictable bowel habits are common in the first few weeks following surgery. Information could include frequently asked questions; thereby reassuring participants that anxieties post surgery are commonplace and providing contact details to be used if they are worried. Providing a realistic picture of what events might occur makes it easier for the individual to evaluate any changes and determine if action is needed (Galloway & Graydon 1996). Taylor's (2007) argument that discharge information is too prescriptive is less relevant to patients who are rapidly discharged home. Taylor (2007) recommends the patient should be prepared for discharge by ensuring sufficient comprehension of body function to enable self management without professional support at home. One example includes the patient taking responsibility for monitoring and recording bowel function to familiarise

themselves with body function and regain confidence. Patients who are rapidly discharged, however, do not have time within hospital to develop this level of knowledge and will therefore be more reliant upon information received at discharge. There is also a need for clear communication between secondary and primary care professionals (Mills and Davidson 2002). This information should include details of treatment and future follow up with copies given to the patient and sent to the GP at the time of discharge (Kripalani et al 2007). This is important to ensure primary care staff have knowledge and information to meet the ongoing needs of their patients once discharged. Finally, hospital professionals could consider the relative merits of a telephone contact within the first week of discharge to assess questions, symptoms and any other issues (Bowman et al 1994; Kripalani et al 2007).

Summary of recommendations

- Individuals should receive written information in a frequently asked questions format, regarding common symptoms following surgery, including pain control, wound healing, suture removal, activity levels and bowel activity.
- Information exchange between secondary and primary care should detail treatment and future follow up plans.
- Hospital professionals could consider a routine telephone contact to the patient within the first week of discharge to assess questions, symptoms and other issues.

6.6.4 Recommendations for ongoing follow up during the first year

Debate continues in the research literature regarding optimum follow up for patients with colorectal cancer (Renehan et al 2004). What is clear from participant's

experiences within this study is that variation occurs, influenced by the individual surgeon, hospital policy, available resources and the relative risk and needs of the individual patient. The primary purpose of follow up may be commonly viewed as surveillance for disease recurrence by health professionals and patients (Li Destri et al 2006; Kew et al 2009), but the supportive aspects of the consultation should not be ignored (Parker et al 2001). One small scale study of women recovering from breast cancer suggested that psychosocial needs remained unaddressed within the conventional, medically led review clinic (McCaughan & McSorley 2007). Patients may feel inhibited in raising emotional concerns if they perceive consultations are focused primarily upon physical issues (Pennery & Mallet 2000). Specialist colorectal nurses are now employed within most acute hospital trusts and are rated highly by patients as information providers (Mills & Davidson 2002). Nurse led follow up clinics have been shown to provide increased time in consultation and continuity for patients (Earnshaw & Stephenson 1997; Strand et al 2010 online) and increased patient satisfaction (Brown et al 2002; Faithfull et al 2001; Moore et al 2002). Knowles et al (2007) piloted a nurse led model follow-up for colorectal cancer patients and observed nurses systematically assessed symptoms at each clinic visit and provided appropriate advice and interventions. Knowles et al (2007) comment that within the traditional medically led follow up, symptom assessment may be undertaken but is not routinely documented. Whilst the evidence base for nurse led follow up is small, advances in treatment and earlier detection are creating a shift in the focus of follow up towards the management of chronic survivorship issues, including delayed side effects of treatment (Lewis et al 2009).

Participants in this study reported longitudinal side effects of treatment which had an adverse impact upon their recovery experience. *Restoring a sense of wellness* required attention and self management of these symptoms. Determining patient

needs and information preferences is the challenge (O'Reilly & Perry 2005). This study suggests that medical led follow up did not provide enough time and attention to fully address these participant concerns. Some research suggests that anxiety levels can actually increase if the doctor offers general reassurance which fails to address the individual's specific cause of anxiety (Donovan & Blake 2000). It is therefore recommended that further consideration is given to the colorectal CNS role and how their advanced assessment skills and holistic approach to patient welfare could be maximised. The CNS may have more flexibility within the follow up schedule to offer a personalised assessment of the individual's recovery. This nursing assessment should consider how the individual describes and defines a sense of wellness, and what priorities and objectives they have for their recovery. Information and strategies for action can then be tailored to the individual. Specific information needs highlighted by participant's in this study included advice regarding diet and fatigue. These topics were not included in the written literature they received, nor were they adequately attended to by health professionals. These findings would support the idea that the content of patient information leaflets should reflect the interests, needs and priorities of patients themselves (Dixon-Woods 2001). Participants in this study did not access alternative sources of information and appeared unaware of local services. It is therefore suggested that all patients should be signposted to local and national agencies, in order that they may access support and information once home.

Summary of recommendations

- Consider the merit of CNS led follow up, where advanced assessment skills and holistic management can be maximised.

- Nursing assessment could consider how the individual describes and defines a sense of wellness, and what priorities and objectives they have for their own recovery.
- Information topics include advice regarding diet, altered bowel habits, fatigue.
- Information leaflets should signpost to local and national agencies for ongoing support and advice.

6.7 Dissemination of findings

The ultimate aim of the Doctorate programme was to develop myself as an advanced practitioner and researcher. This thesis represents the evidence to support my professional development as an advanced researcher. As an essential requirement in fulfilling this role, I have given consideration to the dissemination of the results of my thesis. A summary of the research has been submitted to a national, peer reviewed academic nursing journal. I will submit abstracts to local, national and international conferences. My aim is to influence the nursing and wider cancer community with regards to the needs and experiences of individuals recovering from colorectal cancer. I have forged working links with several voluntary and charitable organisations to discuss future publications and patient orientated literature which addresses the key information needs highlighted by individuals within my study.

As an advanced practitioner, I contribute to a variety of education programmes, both within my local workplace and the wider cancer network. Through these programmes, I am presenting my views regarding nursing roles and a broader conceptual framework by which nurses can assess patient needs. As part of this, I have adopted the grounded theory *Restoring a sense of wellness* as a potential framework to explore patient identified issues, their concerns, as well as their desires

for health and wellbeing. Within my speciality of palliative care, *Restoring a sense of wellness* has profound resonance. Many individuals will be approaching their end of life and yet, *Restoring a sense of wellness* offers an opportunity to explore what is meaningful and important to them, rather than simply focusing upon relief of physical symptoms.

6.8 Summary of chapter

This chapter has presented a summary of the study findings. Themes and implications for clinical practice have been suggested which offer practitioners opportunity to positively influence the individuals' experience following surgery. The limitations of the study have been discussed and recommendations proposed for further research. The original aim of the study was to explore the experiences of the individual following surgery for colorectal cancer. The individual's descriptions of their experiences have shown that recovery is ongoing and evolving. As Glaser and Strauss (1967) comment, a grounded theory is built as an ever evolving process, rather than a finished product and this study requires refinement with other populations. The grounded theory which emerged from the data has potential application within a broader patient group.

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Appendices

Appendix A: Literature Search

The search strategy was developed around the following themes:

Theme 1: Client group including cancer/ colorectal cancer/ bowel cancer.

Theme 2: Information provision including accessibility and issues of equity.

Theme 3: Recovery following surgical treatment.

Theme 4: Concept of illness experience.

Theme 6: Supporting literature from the study of acute and chronic illness.

Inclusion criteria:

- Papers reporting studies applying to adults
- Written in English
- All research designs
- No date limits to avoid excluding important texts.

Due to the large volume of literature, titles and abstracts were initially reviewed for possible inclusion. The numbers of papers found for the topics are listed below in the table.

Databases	Search terms	Results
	Bowel OR colorectal OR cancer AND:	
Cinahl	Information Communication Recovery Surgery Quality of life Illness Experience Health Psychosocial Chronic illness Acute illness Follow up Surveillance Discharge	4259 4281 4259 4280 4267 4255 4318 4280 4256 4255 4260 4258 4258
Medline	Information Communication Recovery Surgery Quality of life Illness Experience Health Psychosocial Chronic illness Acute illness Follow up Surveillance Discharge	39935 39931 39936 40347 39964 39925 40142 40000 39927 39926 40064 39966 39939
British Nursing Index	Information Communication Recovery Surgery	405 405 405 406

	Quality of life	405
	Illness Experience	405
	Health	417
	Psychosocial	406
	Chronic illness	406
	Acute illness	405
	Follow up	405
	Surveillance	405
	Discharge	405
PsychINFO	Information	809
	Communication	804
	Recovery	802
	Surgery	807
	Quality of life	807
	Illness Experience	802
	Health	830
	Psychosocial	801
	Chronic illness	803
	Acute illness	802
	Follow up	803
	Surveillance	803
	Discharge	802
Cochrane Library Systematic Reviews	Colorectal cancer	65
	Bowel cancer	34
	Laparoscopy	43
	Information	1310
	Discharge	188
	Follow up	1131
	Quality of life	987
Psych books; Ovid; ISI web of knowledge; NHS Evidence; Social Sciences Citation Index; Pub Med	Variations of search terms as above.	

Appendix B: The large intestine

The colon and rectum form the last section of the digestive system. The colon is approximately five feet long and extracts water and salts, leaving waste material which is eliminated via the rectum and anus. The colon consists of four sections: the ascending colon, the transverse colon, the descending colon, and the sigmoid colon (the proximal colon usually refers to the ascending colon and transverse colon). The colon, cecum and rectum make up the large intestine.

Figure: The large intestine (IBDUK 2010 online)

TNM staging of colorectal cancer

T stands for tumour

T1 – tumour invades submucosa (inner layer of bowel)

T2 – tumour invades muscularis propria (muscle layer of bowel wall)

T3 – tumour invades through muscularis propria into subserosa (outer lining bowel wall)

T4 – tumour invades into other organs or structures, and /or perforates peritoneum.

N stands for regional lymph nodes

N0 – no lymph node metastasis

N1 – metastases in 1-3 regional lymph nodes

N2 – metastasis in 4 or more regional lymph nodes

M stands for distant metastasis

M0 – no distant metastasis

M1 – distant metastasis

Sobin and Wittekind (2002).

Appendix C: LREC Approval letter

National Research Ethics Service

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The Royal Surrey County Hospital
Egerton Road
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Surrey
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Telephone: 01483 571122 ext 4382
Direct Line/Fax: 01483 406898
Email: ethics.committee@royalsurrey.nhs.uk

Our Ref:07/Q1909/83

14 June 2007

Mrs N Beech
Xxxxx

Dear Mrs Beech

The information journey following primary treatment for colorectal cancer

The Committee was grateful to you and to Dr Arber for attending the meeting of the Research Ethics Committee held on 12 June 2007 when your study was discussed.

Issues discussed

- i. The Committee indicated that it would like to have seen evidence of the impact of a literature review on the design of the study. You explained that you had undertaken a comprehensive literature review. You said also that you would be using grounded theory supported with literature review alongside.

- ii. You confirmed that you would not be using any translation services as you only recruit participants who could fully understand English.
- iii. You were able to reassure the Committee that if any distress occurred during or after interviews you would, where appropriate, offer to refer patients to surgeons, nurses or xxx.
- iv. The Committee noted that in answer to question A39 you had indicated that those outside the NHS would have access to medical records. You clarified the position by saying that Dr Arber would have access to information but without any means of identifying the patient and this had been explained in the patient information sheet.

Ethical opinion

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 documents. The Committee was able to confirm the SSA-exempt status of the study.

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:

- i. NHS REC Application Form, Version 5.3, dated 14 May 2007
- ii. Your curriculum vitae, dated 4 May 2007
- iii. Protocol version 1, dated 24 January 2007
- iv. Letter of invitation to participants, version 1, dated 23 February 2007
- v. Participant Information Sheet, version 1, dated 23 February 2007
- vi. Participant consent sheet, version 1, dated 5 May 2007
- vii. GP/ consultant information sheet, version 1, dated 23 February 2007
- viii. Patient interview schedule, version 1, dated 23 February 2007
- ix. Patient interview schedule 2, version 1, dated 23 February 2007
- x. Patient demographic sheet, version 1, dated 23 February 2007
- xi. Your supervisor's CV, version undated
- xii. Letter from the study sponsor dated 4 May 2007
- xiii. Letters concerning compensation arrangements dated August 2006

R & D approval

You should not commence the study until you have obtained R&D approval for the site/ sites concerned.

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.

Yours sincerely

Co-ordinator

Appendix D: Participant information sheet

(version 2 10.10.2007)

On headed notepaper

You are invited to take part in a research study. Before you decide whether or not you wish to take part it is important for you to understand why the study is being done and what it will involve if you wish to take part. Please read the following information carefully. If you wish, discuss it with your relatives and friends. Also, please ask me if there is anything you don't understand or if you would like more information.

Thank you for reading this.

Q What is the purpose of the study?

A The purpose of this study is to explore the patients information journey following their discharge from hospital after completing primary treatment for colorectal cancer. I wish to find out what information people need once they have been discharged home and how they seek and find this information.

Q Who is organising the study?

A The study is being organised and managed by me. I am a student at the University of Surrey and this study is part of an educational programme. I am a cancer nurse and have experience in this kind of research.

Q Why have you chosen me?

A I would like to talk to people who have completed surgical treatment for colorectal cancer. I would like to invite you to help me find out more about what experiences and issues you have had after discharge home and in particular whether you have specific information needs. I hope to contact 15 patients for this study.

Q Do I have to take part?

A No, your taking part in this study is voluntary. If you would prefer not to take part you do not have to give a reason. The health care team looking after you will not be upset. Your treatment will not be affected and you will receive the usual care.

If you agree to take part in the study and then wish to change your mind, you can also leave the study at any time, without giving a reason or without any effect on your treatment. Also, you may stop the interview at any time you wish, and choose not to answer any of the questions. If, during the interviews, you feel that you said anything you would prefer not to be included, the information will be withdrawn. Your decision will always be respected.

Q What will happen to me if I take part?

A If you agree to take part you will be asked to take part in a total of four interviews. Each interview will last for between 30 minutes and one hour. The first interview will be conducted within 2 weeks of your discharge home from hospital. I will ask you to take part in three more interviews, at three months, six months and twelve months after you are discharged home from hospital. During the interviews I will ask questions about your general well-being, health problems and symptoms. In particular, I will ask about whether you have wanted or needed any information or had any questions about your health. I will ask where you have sought information or asked questions and whether this has been helpful to you or not. With your permission, I would like to tape record the interview. The tape will only be heard by

myself. I would also like to speak to you by telephone in between the interviews, to find out how you are and keep updated with your information needs. To aid your recall, and to provide details for me, I would like to ask you to record any times and methods by which you have sought information in a 'diary' which I will provide.

Q What are the possible risks of taking part?

A For some people certain questions could raise issues that might be upsetting for them. I am an experienced nurse who has talked to many people about their situation. I am aware of the sensitive or difficult problems that some people may experience. Support would be available following the research interview if required.

Q What are the possible benefits of taking part?

A The information that I get from the study will help me gain knowledge and understanding of the needs of people following their discharge home. In particular, this study will help me to identify what information people need and how this should be provided. I hope this information will help health professionals to plan for and provide information for people once they have been discharged home.

Q If I agree to take part where would the interviews take place?

A I would see you at a place and time convenient for you. This could be at your home, or at a local community hospital. The interview would be conducted by myself.

Q Who will see my records and know about my taking part ?

A The only people to see your interview comments will be myself, the researcher. With your permission, I would like to share some of your comments with my University supervisor. Your comments will be anonymous, and the supervisor will not be given any of your personal details, and will not be able to identify you. The information collected about you during the course of the research will be kept confidential. I would want to inform your hospital surgeon and GP that you are taking part, with your permission.

Q What will happen to the information that I give you?

A The findings from the study will be published in a report. All the information you give will be strictly confidential and it will be impossible to identify you in the report.

Q What if I have any concerns?

A If you have any problems, concerns, complaints or other questions about this study, you may call me, Nicola Beech on xxxxx xxxxxx. Alternatively, you may contact your colorectal surgeon or the colorectal specialist nurse on xxxxx xxxxxx.

Q What do I do next?

A If you would like to talk more about taking part in the study, you may either phone me or the colorectal specialist nurse. I will then answer any questions you may have and give you more information about the study.

If you do not wish to take part in the study the surgeon or colorectal specialist nurse will inform me of your decision and you will not be contacted again about the study. Thank you for taking the time to read the information sheet.

Nicola Beech
Nurse Researcher Tel: xxxxx xxxxxx

Appendix E: Participant consent form

Version 1, on headed notepaper

Ethics ref: 07/Q1909/83

I, the undersigned voluntarily agree to take part in the study
"The information journey following primary treatment for colorectal cancer".

- I have read and understood the Information Sheet provided. I have been given a full explanation by the investigators of the nature, purpose, location and likely duration of the study, and of what I will be expected to do. I have been advised about any discomfort and possible ill-effects on my health and well-being which may result. I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given as a result.
- I agree to comply with any instruction given to me during the study and to co-operate fully with the investigators. I shall inform them immediately if I suffer any deterioration of any kind in my health or well-being, or experience any unexpected or unusual symptoms.
- I agree to the investigator contacting my general practitioner about my participation in the study.
- I understand that all personal data relating to volunteers is held and processed in the strictest confidence, and in accordance with the Data Protection Act (1998). I agree that I will not seek to restrict the use of the results of the study on the understanding that my anonymity is preserved.
- I understand that I am free to withdraw from the study at any time without needing to justify my decision and without prejudice.
- I understand that in the event of my suffering a significant and enduring injury (including illness or disease) as a direct result of my participation in the study, compensation will be paid to me by the University subject to certain provisos and limitations. The amount of compensation will be appropriate to the nature, severity and persistence of the injury and will, in general terms, be consistent with the amount of damages commonly awarded for similar injury by an English court in cases where the liability has been admitted
- I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation and agree to comply with the instructions and restrictions of the study.

Name of participant (BLOCK CAPITALS)

Signed

Date

In the presence of (name of witness in BLOCK CAPITALS)

Signed

Date

Name of researcher/person taking consent (BLOCK CAPITALS) NICOLA BEECH

Signed

Date

(1 copy for patient, 1 copy for principal investigator, 1 copy for hospital notes)

Appendix F: Demographic data

Participant Number:

Date of Birth:

Age:

Gender:

Marital status:

Living arrangements:

Race/ ethnic identity:

Religion:

Occupation:

Diagnosis:

Date of diagnosis:

Treatment to date:

Appendix G: Ethics amendment approval

National Research Ethics Service

Surrey Research Ethics Committee

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Telephone: 01483 571122 ext 4382
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18 November 2008

Mrs N Beech
Xxxxx

Dear Nicola

Study title:	The information journey following primary treatment for colorectal cancer
REC reference:	07/Q1909/83
Amendment number:	1
Amendment date:	10 October 2008

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendments form and supporting documentation.

Appendix H: Example of participant transcriptions

Participant Three – Interview One

Interviewer: Could you give me a brief history of what has happened?

P 3/1: How it started? Yes, I went to my GP with blood in the faeces so I have, my mother had bowel cancer and unfortunately she left it and it was, by the time she got to hospital it was too late, it had spread everywhere. So I have always been very aware of it, with all the information you have these days, I knew what to look for and although I had been having sort of indigestion, lower tummy pain, lot of wind, lot of discomfort, night sweats and things. The trouble is I was going through the menopause as well so the whole thing was very confusing. But I did go and see my GP and he did do, he checked me out and did blood tests and I did one of those occult bloods. That was clear. To be perfectly honest he couldn't find anything wrong with me. I am pretty certain they were right but now in my mind, having been, knowing what the symptoms were and I had, I can see in actual fact I think it was starting at least three years ago, very slowly and I think that is what it was, it was giving me the discomfort as well. The menopause caused the symptoms to be mixed up as well. It was very confusing. And then when I saw the blood then I knew that I had to be checked out properly and my doctor sent me to [consultant] and then he said I needed a colonoscopy which my GP had said I probably would have anyway. And then it all went on from there. They found the problem and it was dealt with.

Interviewer: How long was it from when your GP referred you?

P 3/1: Quite quick, I suppose two months, we were just about to go to Cornwall unfortunately when I realised something was wrong. So the week I came back, around [date], I saw [consultant] and then two weeks later a colonoscopy and then it must have been four or five weeks after that I had the operation.

Interviewer: So when did you have your surgery?

P 3/1: [date]. So very, very quick. I was very impressed I must admit. I couldn't have asked for better. The team at [hospital] were very, very good in my respect, I couldn't fault it.

Interviewer: So how have you been since your surgery?

P 3/1: Um, very good considering. I was told I would make a quick recovery because it was only keyhole and I certainly did. I was very careful for two weeks, I did have some discomfort, you would expect it really. Only wind really and painful wind, and some excruciating wind and I was on the point of ringing and I thought no, I'll just leave it a bit longer and it went (laughs). I have been on that point on several occasions, perhaps when this is a bit more than just wind. The only thing that worried me slightly was that in that booklet, I know they have to do it, but they tell you everything that can go wrong and some of it is fairly serious and you seem to think in your mind, is this something serious, should I be doing something about it? That is where you have the security of the hospital, you have someone to ask immediately whereas now you think, I don't want to bother people unnecessarily, but at the same time this is quite worrying. But obviously because of the way I am now, it wasn't, but sometimes the pain was so bad that you did think is this a bit more than you are

supposed to expect and I was told to take off, come off the strong ones as quickly as I could which I can understand, stick to paracetamol which mostly did help and I am not good at taking. I tried not to take unless I was absolutely desperate so I suppose that was the only slight worry I had. But apart from that it has just been a very slow progress of getting stronger and fitter and it has gone very well I have to say.

Interviewer: What about your energy levels?

P 3/1: Good. Almost right from the beginning, yes, because of the problem I had I wasn't absorbing my food properly, I think I probably was a little anaemic and once that had been removed my energy levels were good. I mean I realise now actually how probably not very well I was feeling before. It is having the comparison basically and I was losing weight, I had lost weight for about a year, lost nearly a stone which I suppose I should have thought about but once again I was working very hard [workplace] and it was through the winter period and I just thought it was the work, and I was tired and I just thought that is just the work as well (laughs), it was very difficult to really think, when you try not to think you have something really wrong with you. But now I have got loads of energy and although I am getting older, I haven't got the energy I had in my younger days but if I have a little rest, a cup of tea, I am off again, I am fine and I have gained about four or five pounds which is good. It took a long while, I was beginning to be frightened to get on the scales because I thought oh God, I still haven't put any weight on and I am eating all this food and its not, perhaps there is something else wrong, all these things going through your mind a bit but no, I have put on four pounds which is very good.

Interviewer: Well it is good to put it on steadily isn't it?

P 3/1: I think so, yes, yes because my arms were like sticks and I thought oh gosh I have lost so much and it is probably muscle wastage as well as fat isn't it?
(Interviewer: Mm)

Interviewer: It is very difficult when it happens over time.

P 3/1: Yes, you don't notice it, you don't. But everything seems to be, at the moment, going really well. I still have a little bit of discomfort in my tummy but ..

Interviewer: Have you followed that up with anybody?

P 3/1: It seems to be improving which is why I haven't really. Um, and the bowel habit is a bit erratic, nothing like it used to be (laughs) but I was told it could take 2-3 months, well in the booklet it says it can take 2-3 months for everything to settle down completely so I haven't worried too much about that, just want to be around where you know you are and you've got this, that and the other, you don't want to be in strange circumstances as yet but I am sure I will do, I don't mind going to the pub down the road but I don't want to travel too far as yet.

Interviewer: So if the discomfort hadn't got any better, what would you have done if you had any questions?

P 3/1: Um, go to your GP and see if he can give you something. Because I wasn't sure if I was supposed to take indigestion tablets or not so at one point where it was pretty painful I did chew one but whether it did any good or not I really don't know but it did pass off eventually. It may have been going to anyway but yeah, I would have

gone to the GP. I know [CNS] said I could ring anytime but I think I would probably have gone to the GP first.

Participant Three – Interview Two

Interviewer: So how have you been since I last saw you?

P 3/2: I feel very well, I mean most, virtually all the time, as I saw with the diet, you just have to be a bit careful and experiment with things and some things give you a bit of tummy ache and you sort of avoid that, but whether it is that or not or something else, we don't know but I think I have more or less worked it out now. Yes, I can't eat big meals but then I never could so I eat a little and often which I suppose I have always done anyway for a long time.

Interviewer: How does that fit in with your work then?

P 3/2: Well it fits in quite well really because we go down early, my husband helps me as well, then we come in and have a bit of breakfast and then we go down a do a bit more, I mean every couple of hours, I can't do much more than an hour and a half or two hours of heavy work without having a break anyway so I just come up and have something to eat and then go back down again. So I am eating about ten meals a day (laughs) but it does work quite well in general, yes. Yes my energy levels are good, I am still maintaining my weight which is good, I haven't actually gained vast amounts but I am sticking around 8 stone which is not far off. I used to be 8 stone 2lb/4lb so that is reasonable I think.

Interviewer: What about your strength?

P 3/2: I think probably, I haven't looked at my arms lately but I know before, a few months back I thought oh God, they looked awful, they looked really, really skinny so I don't know whether they have put any weight back but I think my face, people say my face has filled out, I don't look gaunt anymore, even I was noticing it before the operation, I was God I do look really old and thin now (laughs) but I have noticed that has come back, and my colour, my colour has completely come back because I was very pale, because would I have been anaemic with that do you think?

Interviewer: Mm, possibly if you were passing blood.

P 3/2: This is what I thought because, the weight loss obviously, but I was very pale and I was getting a lot of dizzy spells as well which I sort of put down to something wrong with my neck, that is what someone said it was but I don't know, it has all gone virtually now, that is what I am thinking. So much has improved since, it is amazing.

Interviewer: I suppose, did you find it difficult to know actually when you were unwell.....

P 3/2: Yes, and slowly, it must have been coming on fairly slowly so yes, you just think it must be something you have eaten or you haven't eaten enough or this, that and the other. And of course you have menopausal symptoms as well so it is all coming together and you just can't decipher which is which, which is quite difficult really. Yes, so a lot of the things I have noticed now, that were bothering me before, have now gone in actual fact. Yes. I had a lot of lower abdomen discomfort at night particularly and that has just gone, completely which, virtually completely, I mean the odd time, but nothing really like it was but I can remember that for years, could that have been coming on for years? Yes, because I am thinking three or four years, a lot of discomfort at night before I actually noticed the obvious symptoms. Um I keep thinking back over it a lot, I can remember at least 3 years ago feeling, if I can tie it up with other things and think yes I was feeling uncomfortable then but didn't realise,

well obviously you wouldn't I suppose. It is very hard because there is no specific thing you can say oh right, that is definitely that. It is only when you see the blood that you know that something is up. Yeah and you don't feel, well obviously I was feeling ill because I can feel the difference now but people with cancer, you tend to, I suppose you see them at different stages but they look really ill when you see them on the television and I thought well I don't look like that and I am still managing to [activity at work], I thought surely if there was something serious I wouldn't be able to do this but I think it doesn't work like that does it? It is a very slow and gradual process. And it is very hard to pinpoint internal things. Quite frightening really.

Interviewer: Do you look back on it much?

P 3/2: Yes, I do, yes. And I wished, what I wished I had done was insist on a colonoscopy earlier, I think maybe I could have avoided an operation, possibly, if I had had one earlier. I kept thinking about it but obviously because it is not a very pleasant thing, you tend to put it off but with hindsight, a wonderful thing, I know I should have insisted, paid for it if necessary, that is the one regret I have really. The rest I don't think I could have done an awful lot about really so I do think now that because of my mother's history and I was obviously feeling uncomfortable, that was in my mind all the time and I had gone to my GP and he had done various tests but nothing had come up at all but I think with hindsight I should have asked for one really.

Interviewer: Yes, I suppose it is one of those what ifs?

P 3/2: Yes and when one is a bit unpleasant you tend to avoid it. And you certainly don't want to think you have something serious, especially when you seem to be able to carry on, well a relatively normal life.

Interviewer: And how do you feel now?

P 3/2: Oh yes, yes. I feel so much better than I have for a long time, like I say at least 3 or 4 years, or even longer, I don't know. It is good.

Interviewer: When I saw you last time you said you had a bit of lower bowel discomfort, has that settled down now?

P 3/2: Yes, pretty much now, yes, I hardly think about it, hardly notice it. It is just the odd food which, usually very high fibre foods I had to be a little bit careful, I mean I eat a lot of fruit and vegetables, I always have done, I have always had a very good diet compared to what you see on the television, I have always eaten a lot of fruit or vegetables over the last ten years or so, I eat a lot and a high fibre diet but yes, I have lots of exercise and I am outside a lot so things keep moving really well and I think the discomfort is just about gone really.

Interviewer: And how is your social side because I know last time you didn't go out far?

P 3/2: Yes, I did but I don't think it would bother me now. I am too tired by the end of the day to be honest, I don't really feel like it but in the summer I shall do. But I was thinking I wouldn't want to go out in the car very far because you need to know where the loos are but actually I don't think I would need to now. That has settled down to a normal pattern now and I know how to work around it and yes, I don't think it would bother me now.

Participant Three – Interview Three

Interviewer: So how have you been since I last saw you?

P 3/3: I am feeling a lot better actually. I have been trying to fiddle about with my diet, thinking it must be something that I am not eating or something that I shouldn't be eating and I have cut out bread which I always, I have never, I have always been a bit sceptical about food allergies and all that but I thought I am desperate (laughs) and so, I cut out bread and I feel a lot better for it. Whether it is coincidence, whether it is everything just settling down but I am very reluctant to go back to bread because it seems to work. I think it is probably about sort of nearly a week, two weeks since I suppose I have stopped eating it and it didn't make much difference to start with and I thought Oh God, and then after a few days I did start to feel like I was getting much more, longer periods of when I was feeling quite sort of normal inside (laughs). So I don't know, it might be that, but I am going to stick with it. I probably have been feeling, I have some quite good nights, very good nights actually, I haven't had to take any of those tablets, the GP gave me some tablets to try and calm everything down, which did work but I don't like taking tablets unless I really have to so I haven't needed to. Which is good. I mean I don't know whether I have always had a slight, it's a wheat intolerance isn't it? I have heard it is quite common. And I must admit my digestive system has never been very robust so whether it has always been slightly there and perhaps now with the operation and everything, it has made it more severe maybe, I don't know. But at the moment, touch wood, so I feel so much better because I am sleeping.

Interviewer: Was it the pain again then?

P 3/3: Yes, it was. Just a general turmoil inside, it just wouldn't go away. I mean quite often it was very painful and that was horrible and that started alarm bells ringing obviously. But quite a lot of it was just a churning, a constant churning inside.

Interviewer: What did it feel like?

P 3/3 : It felt like wind, but then nothing, it just stayed there, like it was stuck almost which once again I thought Oh God, you know. So I got into panic mode and went to see the GP and she told me I was fine, which made me feel a lot better obviously and the tablets did help quite a bit but they didn't seem, once they, I mean they took a long time to wear off and sometimes I got 24 hours relief from them and whether it was them or not, I don't know. But then it would come back again and I thought oh dear, I am going to have to take these forever and I didn't really want to. And it didn't seem to be, the first one worked really well and then I found that they weren't quite so effective, a few days later it wasn't having quite the same effect and I thought oh dear. But this sort of non bread thing, I mean I miss toast desperately but if it is making me feel better, I don't care. I mean so far it is certainly working and I just feel completely different. For one thing, the worry has gone away which probably helps a lot but I definitely feel, I can feel when I am normal and when I am not now. I think because I was so abnormal for so long, it almost became normal (laughs). And now when everything is still and normal and quiet, I think gosh, this is how I should feel and I must admit, most of the time, 80% of the time, I do feel like that now. So I am hoping, I am hoping that is what it is. Because I can eat porridge, oat based, because I love biscuits and cakes, I love them, I can eat, I seem to be able to eat flapjack and things like that which are purely oats and haven't got any wheat. Some of the biscuits, they put a bit of wheat in, so I have avoided those. I am being very

strict about it. I haven't tried pasta yet. It is just that, having been so uncomfortable and then feeling what it is like, I am just so wary of trying anything with that in as it seems to be working. I mean I am occasionally tempted to think, oh just try a bit of toast, but if it is going to bring all that discomfort back, I don't want to do it.

Interviewer: So were you having to take the tablets pretty much every day?

P 3/3: Well no. The first one worked really well and I got a good 24 hours relief and I thought oh right, I won't take one, perhaps things have settled down a bit and then it started to come back again. I only used to take 2 at night, 1 at night. I could take up to 1 three times a day but I just took one at night because during the day, I think I said, when I am moving around, I tend to forget about it, I don't really notice it that much, it is just literally lying in bed in the early hours with it all going on, it was just really, really unpleasant so I just took one at night and then I took it again when I thought oh well, I might as well have a decent night tonight. And it didn't work particularly well. It was alright but it didn't really take it away like the first one did. So I did take them more regularly after that but I must admit as soon as I decided to cut out bread, everything else has settled down.

Interviewer: So about ten days ago?

P 3/3: Yes, about ten days ago. It has virtually gone. Just occasionally I get a twinge or a bit of discomfort but it doesn't seem to be anything like it was.

Interviewer: I think when I saw you last time and then we spoke on the phone, you were saying it came and went. Was it getting more frequent?

P 3/3: Yes, it was, it definitely was. And during the day time sometimes as well but I mean it may not be that at all. It may be that things have just, it has coincided with things settling down, I don't know. It has been 9 months now which I suppose isn't that long since it was done. I know nerves and things take a long time to adjust.

INTERRUPTED FOR PHONE

Interviewer: So it is a lot better then?

P 3/3: Yes, a lot better.

Interviewer: Did they give you any advice about diet?

P 3/3: No, because I did say should I be careful and they said no, just eat what you like. I suppose nothing was actually going to do me any harm as such but I suppose some things are more difficult for me to deal with than others. I must admit, in general, everything else, I used to think oh gosh I have eaten too much fruit and fibre and it is, just can't cope at the moment, so I sort of cut down on that but I have eaten lots of fruit just lately and lots of salads and things like that, and I am fine. It doesn't do anything. It just seems to be bread.

Interviewer: Do you drink a lot of milk?

P 3/3: Yes, but that doesn't seem to have any effect. I am eating yoghurts and egg, yeah, quite a bit of milk in the porridge, yes, doesn't seem to have any effect. But I have never ever given up bread before. I have tried giving up other things like milk and eggs and cheese and it hasn't really made any difference but this is the only

thing that has ever made any difference, so I am just hoping to God that is what it is (laughs).

Participant Three – Interview Four

Interviewer: So how have you been since I last saw you?

P 3/4: I think I'm O.K. I'm fine, I feel pretty good at the moment um.. I've had the odd few days when on and off I've had a lot of tummy pain. It's usually at night. I'm fine during the day, probably because I'm moving around and everything is moving fine. It tends to be in the early hours of the morning, around 2 or 3 o'clock in the morning, I get a bit of sort of, I suppose it's a sort of windy pain or something like that. It happens, it used to happen every single morning. Last night was O.K. Whether it's due to what I eat, I mean I keep experimenting with diet and this and the other. I mean, I think, at the moment I think it's probably nuts and dried fruit because I ate a little bit of that over Christmas and that gave me quite a lot of tummy pains and I thought oh well perhaps it's that, so I stopped that completely (laughs). I'm not sure about eggs, I'm a bit iffy about eggs, I haven't had any for a while so I don't really know whether to have any or not. I'm just enjoying, last night I had probably a good night, one of the best nights I've had in ages and I thought well I don't quite know why but I am not going to try eggs just yet. I'm going to have a few better nights first. Yeah, it's very difficult to pinpoint exactly why this is happening. Everything else seems to be fine. I feel well, I've got lots of energy, there is no, you know, worrying symptoms apart from the pain at night but I can function perfectly well during the day and do all my work and be outside and on the move the whole day long without feeling absolutely exhausted or anything like that so I assume everything's alright.

Interviewer: Because you were talking about bread or pasta last time.

P 3/4: Yes I was. No, no, not at all. I don't think it is that. That wasn't causing any problems at all, I eat quite a reasonable amount of bread now and eat pasta, well I did yesterday and it had no effect so I mean, I don't eat a lot of fresh fruit to be honest, I eat a lot of cooked fruit and vegetables but not fresh fruit so much. I drink those smoothie things because they are probably easier to digest. I'm not sure really. I can't say for sure, definitely, what's causing it. And maybe it is just a question of giving it more time you know, it's been just over a year and I've had no experience of this before but I know with animals that have had gut operations, it's taken a long, long time before they've got back to normal. You are talking 18 months so I don't know whether it's the same in humans but perhaps there's little nerves and things that need to adjust or perhaps repair or something. I think things in your tummy at night always hurt a lot more than moving around during the day so I probably notice it a lot more at 3 o'clock in the morning than perhaps I would in the afternoon when I just sort of, oh that hurts a bit and then just carry on. It just goes off and I haven't even noticed it's gone.

Interviewer: And your bowel rests at night so perhaps....

P 3/4: I think yes, things get a bit stagnant perhaps and I must admit as soon as I get up in the morning and have a cup of tea and walk around, any pain I've got goes. It just goes. I can be lying there for hours thinking oh God, that hurts a bit, hurts a bit and I can't wait to get up and as soon as I get up I'm alright.

Interviewer: Does it wake you up?

P 3/4: Um, I'm not sure if it wakes me up or if I wake up and then I notice it. I'm not quite sure about that at the moment. I have always been a bad sleeper. For years and years, and I very rarely get a good night's sleep um so it could be that I wake up and perhaps a few twinges there, which if I'd been asleep I would have slept through.

I don't know, I don't know. It's very difficult to tell but I take those, they're called C... mint oil tablets sometimes which seem to help quite a bit actually. They are for IBS which I think is probably what I've got actually, just mint oil in a tablet, quite expensive but they do help, I think, to a large degree. I don't have to take them all the time but ...

Interviewer: Are these things you just take as and when you need them?

P 3/4: Yeah. Just mint oil. Peppermint is recommended for lots of things. I think they do. I mean I don't think they would help if you got really, really severe tummy pains but certainly if you've got a bit of irritating pain it seems to get rid of it.

Interviewer: What is the pain like?

Patient 3/4: It varies. Sometimes it's just a sort of, niggling little gripeyness and other times it squeezes and is really quite painful. It feels like a trapped wind. Sometimes I get, well the operation site was around here somewhere, sometimes I can feel that hurt a little bit but it's not, that doesn't bother me too much. It's more windy pains that can be quite uncomfortable. They make me get hot sometimes, I lay at night feeling a bit hot and sweaty and the pain's gripping. You know as I say, I mean in every other way, everything seems to be absolutely fine so all I can assume is that's all it is. Obviously you have the odd little bit of worry sometimes, thinking Oh my God...

Interviewer: is it a different sort of pain?

P 3/4: Yeah, but I had a lot of other symptoms alongside it before. There was the blood and the weight loss and tiredness, you know, those were the main symptoms more than anything. Yes I did get pains in my stomach and although they were, some of them are a little bit similar, I suppose any stomach pain is going to be similar. Not as severe, no. Sometimes it was quite severe.

Interviewer: Maybe that is your bowel now?

P 3/4: It could be, yes. I think probably it is. I think, I always have not had a particularly settled bowel, I don't think. Perhaps I was born like that, it could be. I keep to the same routine all the time and I always come to the house if I need to, you know, it's not restricted.

Interviewer: Have your bowel habits settled into a routine?

P 3/4: Yeah, pretty much, yes, yes. No problems. Everything seems pretty normal really.

Interviewer: and you've put on weight?

P 3/4: I'm not sure. I haven't weighed myself actually. I think I have, I can feel a little bit more flesh on me. I think so. I looked a little gaunt before. Even I can notice that now. I avoid the scales because I don't want to see if I've lots weight, I don't want to know. I'm sure I haven't because things feel normal, you can tell because things start to feel so loose and they sort of hang off you and you don't fill your clothes properly and then you know you've lost weight. I'm not like that. I can feel that everything feels quite normal.

Appendix I: Examples of coding categories

Narrative exemplars	Subcategories	Categories	Conceptual phase
"I went to the toilet and when I opened my bowels there was blood."	Acute symptoms	Body disruption	Disrupting the self
I just seemed to have diarrhoea all the time and in the end I mentioned it to the doctor." (4/1)	Chronic symptoms	Body disruption	
"Literally it was, I think I must have been fast tracked, it was so quick." (9/1)	Rapid treatment	Medicalisation	
"I didn't actually want to find out anymore, maybe a bit like head in the sand." (3/1)	Cancer diagnosis	Emotional disruption	
"I'd been getting more and more tired, and just couldn't put the hours in." (12/2)	Loss of valued role	Functional disruption	
Narrative exemplars	Subcategories	Categories	Conceptual phase
"Every day and every afternoon I got a bit further and further and further till eventually I walked to the shop and back." (6/4)	Resuming activity	Repairing the body	Repairing the self
"It's a sensation which when I band over or sit down on a chair, in and out of the car, I really get this stabbing feeling." (9/1)	Body monitoring		
I know about diarrhoea from before the operation" (8/2)	Comparing		
"I had said I didn't want chemotherapy... it felt right to be saying I'm not going to have it." (8/1)	Expression of voice	Reclaiming control	
"They didn't want to see me again after that." (3/4)	Follow up	A sense of loss	
"And more time to ask questions because you get home and you think, oh what did they say about that." *8/4)	Information seeking		

CHAPTER 7: RESEARCH LOG

7.1 Research Log

This research log summarises the advanced research skills and knowledge I have acquired throughout the Doctorate in Clinical Practice Programme at EIHMS, University of Surrey, 2005-2010. I have completed journal notes, field notes and a reflective diary throughout the programme as a form of governance for my research project, and to demonstrate rigour within my chosen methodology.

7.2 Developing research awareness

I started the Doctorate Programme with some research experience. I had completed a Masters in Professional Studies ten years previously, and had worked as a research practitioner under supervision from a Professor of Cancer Nursing. As part of the Introduction to Doctoral Studies module, I completed a learning needs analysis and critically reflected on my existing skills and knowledge. Areas I needed to develop as a doctoral student and an advanced researcher included knowledge of advanced research methodology; and skills regarding systematic and critical review of the literature (table 1).

7.3 Refining the research question

The formative assignment of the topic review required me to critically examine an area of my clinical practice to inform my future project. My clinical observations as an information officer suggested individuals continued to have unmet information needs

Skills/ Knowledge	Areas to develop	Notes/ action plan
Studying skills for Doctorate level	Time and project management skills	Dunleavy P. (2003) Authoring a PhD: how to plan, draft, write and finish a doctoral thesis or dissertation Oliver P. (2004) Writing your thesis Study skills seminar Reflective researcher log
Knowledge and understanding	Advanced research methodologies Policy agendas; clinical context; health service	Modules within taught element. Wider reading, electronic alerts.
Cognitive skills	Critical reading & analysis, systematic review, synthesis, report writing. Advanced conceptual and theoretical understanding	Library skills seminars; database helpsheets; Endnote Introduction to Doctoral Studies module/ Advanced Research Methods.
Transferable skills	Strategies for dissemination	Writing skills; supervision process; wide reading. Submission to conferences; post graduate seminars.

Table 1: Skills and knowledge to develop (Research Log 2005)

after completing treatment for cancer. Literature reviews were conducted to test out potential research questions by identifying where areas were undeveloped (table 2). Reviewing the literature suggested less research had been conducted with colorectal cancer populations, and that existing research was weighted towards quantitative methodology. I therefore became interested in exploring how the individual experienced recovery after curative surgery for colorectal cancer. I was curious to

know if the individual had information needs and if so, how these were addressed. Individuals completing surgical treatment for curative cancer were less likely to have regular contact with health professionals outside of the outpatient clinic, unless initiating contact them self.

Topic/ subject area	Key subject areas	Topic areas for each subject
Colorectal cancer	Post treatment	Recovery; information needs; follow up
Information and support	Provision; location and mode of delivery	Location and setting; User/ provider interactions; complex interventions
Equity of services	Equity, barriers, accessibility; usability	Access; marginalised people, location and provision of services

Table 2: Topic/ subject area (Research Log February 2005)

To supplement the literature searches I set up regular alerts and notifications from policy and health care sites; and journals which regularly published articles of potential relevance (table 3). Once data collection was underway, literature searching was temporarily halted to adhere to the principles of grounded theory which state that the literature must not be consulted to avoid `tainting` the data.

Email Alerts set up:	NICE website PM website Direct government HTA programme Policy hub Online journals including BioMed Central; BMJ; Journal Advanced Nursing; Palliative Medicine; SAGE publications; Springerlink.
Checks for official publications:	Department of Health

	Department of Treasury Department of Deputy Prime Minister NICE London's Health NHS Modernisation agency Policy hub HTA programme
Websites	Kings Fund Health services management centre Social research National primary care research and development centre PubMed Patient Information Forum (member) http://www.groundedtheory.com/ http://www.socialresearchmethods.net http://www.nhsconfed.org
Libraries	University of Surrey Institute of Cancer Research (visitor) Royal College of Nursing (member) King's Fund Local town library (member)

Table 3: Alerts and notifications (Research Log July 2007)

7.4 Networking

To ensure my ideas were relevant and grounded in clinical practice, I set up networking with stakeholders who had an interest in information provision; colleagues from the wider cancer network; national organizations' who provide information services; and representatives from a local cancer user group (table 4).

Stakeholders	Notes
Information Services Manager	Experienced in provision and development of information

	services
Primary Care Advisor	Information in wider community setting
University colleague	Issues surrounding literacy, access to information
University lecturer	Used grounded theory
Cancer user group	Interest in “user” view
CNS	Monthly meetings at MD team

Table 4: Stakeholders (Research Log July 2005)

7.5   *Methodological considerations*

In keeping with the naturalist paradigm where social context and processes are acknowledged for their impact upon beliefs and behaviours, I decided a qualitative approach was appropriate. Grounded theory was chosen as it is underpinned by symbolic interactionism; where the emphasis is upon the natural world of human behaviour. Symbolic interactionism facilitates the exploration of how patients interpret and interact within their world; giving attention to social structural contexts.

7.5.1   *Sample*

I chose the location for my study with the support of one of my colleagues in the cancer network. I sought approval from the two clinical leads for the colorectal department to access their patients. The research proposal was finalized and submitted to the local research ethics committee; NHS R & D department; University Ethics. I had previously made submissions to ethics committees but I ensured I updated my knowledge of standards; good research practice; and current ethics submission guidelines. Once ethical approval had been granted, I began attending the weekly multi-disciplinary meetings with the colorectal team. This served to

familiarize myself with the team and patient care; to collect contextual data; and to facilitate patient recruitment.

7.5.2 Data Collection and Analysis

The initial proposal had stated patients would be interviewed twice: once on discharge and then three months later. However early data analysis indicated that patients continued to have issues regarding their recovery and access to information after this time. I therefore applied to ethics for a substantial amendment, to interview patients every three months up to one year post surgery. This process was straightforward and approval was granted. Modifications to the data collection also fitted well with the principle of grounded theory and letting the data speak for itself.

7.6 Challenges

I had several changes of principal supervisor during the first three years of the programme due to staff changes within the University. I also had two changes of employment, culminating in a move back into a clinical role. These experiences created difficulties with regards to study leave and time for studying, setting a timetable for supervision, and determining and adhering to the schedule for the project.

7.6.1 Data management and NVivo

One of the most complex aspects of the research project was managing the volumes of data and analysis. I had attended a workshop on using QSR NVivo in year two and so decided to pursue this further. I accessed taught workshops; online tutorials and talked to other colleagues about their experiences. As a consequence of

discussions with colleagues, I began to use NVivo to record my literature reviews and critiques which greatly aided the writing of the discussion section of the thesis as I was able to quickly cross reference my data analysis to the literature.

7.6.2 Writing the Thesis

As I progressed with data analysis, I produced numerous memos and field notes. Memos were written about data analysis and emerging themes; conceptual and theoretical topics; supervision. The memos then provided a framework for writing the thesis. Producing the first drafts of the thesis was difficult, partly due to a busy work schedule and no study leave, but also because I needed to develop my writing skills. Widespread reading from a range of peer reviewed academic journals and academic texts, and supervision, gradually informed my writing skills to become more succinct, relevant and critical.

7.7 Dissemination

I attended research seminars hosted by the University of Surrey; King's College London; and local NHS services. These seminars served to broaden my research knowledge and skills whilst also providing a forum for me to discuss my ideas and project with other colleagues. As I progressed through the programme, I took advantage of opportunities to present my work in more formal settings and to wider audiences. Two significant events served to boost my confidence and my skills at disseminating my work. The first was winning the RCN Marjorie Simpson Novice Researcher's Award 2007. For this award I had to submit a summary of my project, including the rationale for the topic area and how I anticipated it would enhance nursing practice. Attendance at this conference enabled me to develop contacts with

other researchers who had used grounded theory; two of whom provided much support and encouragement throughout the analysis and writing up stages of the thesis. The second opportunity to present my work was at an international conference for European Nurses as part of the Medical Oncology Society. This represented the first major oral presentation I had undertaken and was a significant stepping stone in my research development.

7.8 Conclusions

Reflecting on my progress through the programme, I can identify how I have developed as a clinical specialist and advanced researcher. I now work in a clinical role providing specialist nursing services to a diverse client group. I develop and contribute to education programmes within and external to the organisation. I am a member of strategic, policy and research management groups, and have initiated research to address issues pertinent to the organisation and patient care. On a personal note, I am more confident and vocal in expressing my views, and entering into discussions with others.

Appendix 1: Supervision Record

Date	Discussion	Action points
06/12/05	Defining health information; Link to service development project - issues equity and accessibility; information needs over time	1. Contact user group. 2. Literature on equity. 3. Literature on information access and use.
06/06/06	Protocol for project; core literature regarding information and cancer services	1. Complete protocol 2. Summary of key literature (3-4 pages). 3. Work on definitions.
26.09.06	Defining health literature; equity; changing needs over time; methodology - grounded theory	1. Schou and Hewison - experience of cancer. 2. Review grounded theory
13/09/06	Plan for forthcoming meeting re. sample	1. Meet NHS colorectal CNS and surgeons re access.
02/02/07	Ethics submission; University ethics; NHS honorary contract	1. Contact NHS governance lead. 2. Obtain and schedule submission to ethics.
02/06/07	Ethics meeting	1. Prepare for meeting; review protocol.
21/01/08	Discussed patient one interview, particularly use of language. Talked about nvivo and how to begin coding process.	1. Patient 2 interview. 2. Continue line by line coding. 3. Develop NVIVO skills.
02.04.08	Consider literature regarding pre diagnosis phase. Ongoing recruitment and analysis.	1. Develop coding themes. 2. Literature re pre diagnosis - key themes.
19.05.08	Coding themes, use Nvivo, use	1. Develop model of 'beginnings'.

	diagrams/ models.	2. Broader literature re support.
07.08.08	Extending recruitment, ethics amendment	1. Prepare and submit amendment. 2. Review ethics dates.
05.11.08	Recruitment, critical time points, extended data collection and recruitment	1. Draft key themes with properties and categories. 2. Literature re researcher role and active participant.
08.01.09	Via Telephone. discussion re properties and categories; axial coding.	1. Develop one theme and properties. Consider over time.
14.01.09	Key theme of bowel disruption; disruption to life.	1. Review Bury and biographical disruption. 2. Develop analysis and discussion after each data excerpt.
26.01.09	Data analysis, axial coding	1. Continue writing draft analysis. 2. Develop more themes/ coding
11.05.09	Via email. Themes, draft chapters	1. Continue working on axial coding/ themes. 2. Methods chapter - make reference to my project.
03.08.09	Methods and methodology chapters	1. Minor adjustments once data collection complete. 2. Plan for other chapters.
21.08.09	Via email. Storyline.	1. Storyline as framework for analysis chapter.
03.09.09	Coding and writing up analysis	1. Further refinement for analysis chapter.
05.09.09	Via email. Analysis themes.	1. Concept of recovery - issues of medicalisation; elements of time.
23/10/09	Analysis themes; supporting literature.	1. Develop sections and sub

		sections for analysis chapter.
25.11.09	Via email. Analysis themes.	1. Knowledge, lay experiences.
22.03.10	Via email. Analysis themes.	1. Threats to identity working well. 2. Continue with theme of repair and then restoration.
10.06.10	Timelines re submission; chapter outlines and timetable.	1. Final draft analysis. 2. Discussion chapter.
12.07.10	Literature, discussion key findings.	1. Finalise discussion chapter. 2. Finalise literature review.
10.08.10	Data analysis chapter. Via email - studies regarding survivorship.	1. Intro - clear introduction. 2. Refine diagram. 3. Concept medicalisation and applicability to treatment pathway.
16.08.10	Via email. Data analysis chapter.	1. Emotional and psychosocial issues. 2. Topics for discussion chapter.
05.09.10	Via email. Discussion chapter.	1. Clarity conceptual vocabulary from chronic illness literature. 2. Strengthen relevance of existing literature to my study.
30.09.10	Discussion chapter, literature review.	1. Minor changes to discussion chapter. 2. Literature review - areas and flow. 3. Confirm submission procedure.
22.10.10	Literature review. Viva. Article	1. Revisions to literature review. 2. Final review methodology chapter. 3. Framework for article.

19.11.10	Via email. Methodology chapter.	1. Review and editing.
30.11.10	Via email. Methodology/ methods chapter. Article	1. Final editing. 2. Revisions for article, submission.

CHAPTER 8: OVERVIEW OF KNOWLEDGE, RESEARCH AND PRACTICE

8.1 Introduction

This paper presents a reflective account of how the taught elements of the Doctorate in Clinical Practice programme (DClinPrac) and the research project have contributed to the integration of research knowledge within my clinical practice. The DClinPrac programme is delivered in four phases with regular summative and formative assignments (table 1). I discuss these assignments to illustrate my knowledge acquisition and discuss how this knowledge has been implemented within my clinical practice.

Year 1	Learning needs analysis Topic review Policy review: Better Information, better choices, better health
Year 2	Service development project: Accessing health information Research protocol: Recovery following treatment for colorectal cancer
Year 3	Research project Supervision
Year 4	Submission of thesis and part II

Table 1: Assignments throughout the Doctorate Programme

8.2 *The taught elements of the programme*

The six taught modules of the programme are delivered throughout years one and two. From the outset, I was encouraged to identify links between my clinical practice and the taught elements. Within my work in palliative care, I had used reflective practice and experiential learning to inform my clinical and professional development and I was keen to utilize these skills within my academic study. The learning needs analysis required me to consider my own strengths and weaknesses as a practitioner and novice researcher, in relation to the learning outcomes for the programme. I identified some key areas for development throughout the taught elements of the programme, and in particular, the development of critical thinking and theoretical awareness (box 1).

Knowledge and understanding -	Research paradigms and methodology Critical thinking
Cognitive skills -	Data analysis and managing complexity of data Articulation of process and outcomes
Practical skills -	Contextual issues influencing area of work Strategy and service development
Key transferable skills -	Self appraisal and reflexive practice Presentation to wider audiences

Box 1: Areas identified for development

8.3 *Topic review*

This assignment provided the opportunity to review an area of clinical practice and begin developing ideas for a possible research project. Initially I had a very broad

topic area I wished to consider. The introduction to Doctoral Studies module was vital to this process as sessions included search skills for evidence retrieval and critical analysis and synthesis skills. Using critical appraisal, I began to review the literature to identify areas which were theoretically undeveloped and warranted further research. My ideas were firmly grounded in my clinical practice as an excerpt from my research log illustrates (box).

I am interested in the issues surrounding providing information and support within a community setting. My clinical practice to date has identified that certain groups i.e. those outside secondary health care systems have largely unmet information and support needs. My questions/ area: What are the issues with relation to providing information and support to those in the community who do not have access/ are not receiving care from secondary health care services?

Box: Topic review (notes written February 2005)

The Advanced Research Module was particularly stimulating at this time. Several sessions involved detailed class discussion regarding paradigms and how an individual's epistemological stance influences how they approach a topic area. Lecturers encouraged me to consider how I was influenced by my personal and professional background. One discussion in particular focused upon the polar opposites of positivism versus anti-realist. I recognized that whilst I had a very strong affinity to an anti-realist paradigm, much of my previous research experience was firmly rooted in a positivist stance. This explained why my previous research had often felt uncomfortable and unwieldy. Reviewing and reflecting upon clinical practice

also suggested that much of my previous experience was within organisations underpinned by a biomedical framework. As a nurse I attempted to operate within a naturalist paradigm but organizational structures made this difficult at times. At this stage I became aware that I wanted to use a research methodology which allowed me to explore an aspect of nursing practice from the patient's viewpoint.

Completing the topic review required me to develop skills of reviewing a broad subject area before moving to a detailed and critical review of specific topic areas. These skills of critical questioning, enhanced appraisal skills and application of a wide knowledge base have also informed my clinical practice. As a specialist practitioner I provide evidence based care to patients on my caseload. I contribute to monthly significant event analysis meetings during which we critically appraise our performance against standards of practice and the latest research evidence. I support colleagues in reviewing the literature and implementing best practice based upon current knowledge. Through widespread reading, knowledge gained during modules on the programme and class room based discussions, I am now able to incorporate enhanced professional knowledge and expertise into my clinical practice.

8.4 Policy review in a specialist field

The policy analysis was the first summative assignment and fundamental in setting the context for my research project (see Policy Analysis Part II). Prior to the taught element, I was relatively naïve regarding policy influences within my clinical environment. The policy I chose was topical to my area of work at that time as an information officer. At the conclusion of the assignment, I had questions regarding the introduction and adoption of policies through a top down approach. I was keen to consider global, national and local aspects which potentially influenced the

development and implementation of policy. My clinical experiences questioned whether a policy could be introduced into practice without due consideration of the resources required for delivery. My learning from completing the assignment highlighted the distinction between availability, accessibility and usability of information.

After completing the policy module, I am better able to critically appraise national and local policy statements within my practice. Completing the assignment has given me confidence to engage into discussions regarding policy in my workplace. I have contributed to the development of a research policy, and multiple clinical protocols, within my organisation. I have given consideration to the wider community within which we work to ensure policy is relevant and widely implemented. I work with colleagues in primary and secondary care, and policies within our organisation have to "fit" with those of other agencies. This cross boundary working has been informed and influenced by my learning from the Communities of Practice module, in acknowledging group and organisation attitudes and beliefs which impact upon the adoption of policy.

8.5 *Service development project March 2006*

The Service Development Project (SDP) enabled me to conduct a small study as development work for my research project (see part II). The policy analysis had identified the potential for discrepancy between policy statement and the reality of clinical practice, raising questions of how organisations can achieve equity and accessibility. The ethics module emphasized the wider issues of organisational ethics including freedom of information, professional ethics of team work, professional decision making and competence. Of particular relevance to my

developing ideas was the issue of fair resource allocation. I was keen to focus on the underserved within information services and needed to identify a potential community in which to conduct my SDP. I approached a user group of cancer patient representatives, to seek their views and experiences regarding information provision and acquisition. Their comments suggested limited opportunities existed for information acquisition within secondary health services, and that information needs continued following discharge home. It therefore became clear that a longitudinal approach would be required to consider the ongoing nature of information needs.

The wider issues of organisational ethics and equitable service provision have implications within my working practice. My clinical role requires me to work as an autonomous practitioner; within a small team of three covering one geographical location; and as part of the large community team. Issues of ethical team working and decision making are paramount. I am currently working with a lecturer practitioner to develop education programmes to promote cohesive team working, and facilitate ethical practice. Recognising and accommodating individual preferences and values, as included in the communities of practice module, has been essential to ensure all individuals are committed to the education programme.

8.6 *The research project*

My decision making regarding the methodology for my research project illustrates my learning throughout the DClin Prac. I wanted to explore the experiences of the individual after treatment, and therefore sought a path of discovery. I adopted a naturalist approach for the study where my clinical practice, beliefs and values were acknowledged for their potential influence on how I conducted the study. Symbolic interactionism provided the conceptual framework as this theory assumes society,

reality and self are constructed through interaction, and that meaning will influence behaviour. Grounded theory was a new method for me, but one that would enable me to generate knowledge about behaviour patterns in a particular context. I was interested in how an individual's interpretation of their experience would be influenced by their health and contact with health services.

Themes from the taught module on emotions, leadership and innovation in organisations were fundamental to my research project. A session on chaos and systems thinking stimulated me to consider issues regarding team working. Wheatley's (1999) work on information within organizations focused on information sharing as the primary organizing force in an organization. I began to think about organizations in the broadest sense; both teams within health care settings, and the health organization itself. I drew on learning from the communities of practice to inform my sampling choices and recruitment. I developed links with colorectal specialist nurses who then assisted with refining my sampling criteria and recruitment process. I considered the wider community of secondary health care, where specific policy, ethical and clinical practices must be acknowledged. Seeking permission from stakeholders within the Trust required a clear articulation of my research project rationale and aims. Confidence as a public speaker arising from learning within the Leadership module greatly assisted me when presenting my study to representatives from the colorectal team.

Gaining approval from the Research Ethics Committee, the NHS Trusts Research and Development Committee, and University Ethics promoted confidence in the relevance and importance of my project. The Research Ethics Committee had questions regarding what they perceived as a lack of a literature review within the proposal. My skills and developing confidence in discussing my project were

influential in explaining the purpose of the literature review within grounded theory methodology, and the rationale for postponing the substantial literature review until data analysis was underway.

8.7 Dissemination

Disseminating the results of my study will draw upon my leadership and communication skills. To date I have concentrated predominantly on informing and disseminating my knowledge within my local work environment. This is partly because I am new to my clinical specialist post and have had to acquire a lot of specialist knowledge within a very short time frame. I recognize that I now have an appreciation of the ways to influence others, identified through the module on communities of practice. I have outlined two significant opportunities to present my work in formal settings (see research log), and have plans for future presentations to national nursing and professional forums. I am also developing links with a voluntary organisation to discuss the utilisation of my research findings within some of their publications. Confidence and heightened awareness of how an individual can influence the political agenda has enabled me to identify a wider range of methods by which I can disseminate my work.

8.8 Conclusion

The work I have undertaken for the DClinPrac has been instrumental in my professional and personal development as a clinical expert and advanced researcher. I now have advanced research skills which enable me to identify and initiate projects to fulfill my professional obligations as a clinical specialist. My ultimate aim is to improve the experience of patients who require health services. My research project

has identified implications for nursing practice which offer practitioners the opportunity to positively influence the individuals' experience following surgery. I believe the findings are also relevant to a wider patient group. The skills I have developed through the DClinPrac provide a medium by which I can interact and influence the wider community of health professionals.

Doctorate in Clinical Practice

PART TWO

Clinical Academic Paper

Policy Review in a Specialist Field

Service Development Project

Faculty of Health and Medical Sciences

Division of Health and Social Care

University of Surrey

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Restoring a sense of wellness following colorectal cancer: a grounded theory

9.1 Abstract

Aim: This paper reports a study to develop a grounded theory to explain the experience of recovery following surgery for colorectal cancer.

Background: Studies have adopted a biomedical framework to measure quality of life and symptom distress following surgery for colorectal cancer. These studies suggest symptoms of pain, insomnia and fatigue, may persist for many months following treatment. Fewer studies have considered the individual's experiences and perspective of the emotional, social and cultural aspects of recovery.

Methods: A longitudinal study using grounded theory was conducted with 12 individuals, who had received surgery for colorectal cancer. Semi-structured interviews were conducted at 4 time points over one year following surgery, between 2007 and 2009. Grounded theory analysis was undertaken using Strauss and Corbin's framework.

Findings: Recovery is described in three phases: disrupting the self; repairing the self; restoring the self. The core category is Restoring a sense of wellness; fostered through awareness and enjoyment of the physical, emotional, spiritual and social aspects of life. A sense of wellness exists as a duality with a sense of illness, where both perspectives may co-exist but one usually takes precedence. A sense of illness pervades when the individual is preoccupied with illness and the illness continues to disrupt their daily life.

Conclusion: Recovery takes time and energy, particularly when the individual is at home and in relative isolation from health professionals. Opportunities exist for nurses to provide information and support to facilitate the individual in their progress towards achieving a sense of wellness.

9.2 *Summary statement*

What is already known about this topic:

- Colorectal cancer represents a significant disease burden worldwide, and surgery is the definitive treatment for localised disease.
- Existing research has often adopted a biomedical framework where recovery is measured through sequelae of treatment and assessed against quality of life scores.
- Studies suggest physical symptoms such as pain, insomnia and fatigue are persistent, and can influence emotional and social functioning.

What this paper adds:

- This study illustrates how social and cultural meanings associated with colorectal cancer create an illness episode beyond the immediacy of curative surgery.
- Colorectal cancer and medical treatment disrupt a sense of self identity, and recovery is then a process which aims to restore a sense of identity.
- Recovery is more than simply a process of physical body repair.

Implications for practice:

- Protocols between health professional teams (including primary and secondary care) will prevent ambiguity and enhance consistency regarding responsibility for providing information throughout the treatment pathway.
- Discharge information is required in written format which outlines common experiences following surgery. Clear signposting to local and national sources of information and support must be provided.
- Consideration should be given to the merits of telephone contact by a health professional within the first weeks of recovery to assess progress and elicit any patient concerns.
- Nurse led follow up clinics suggest increased time in consultation and continuity for patients, and enhanced patient satisfaction. This style of service may be appropriate for patients who experience longitudinal consequences from treatment.

KEY WORDS: nursing; colorectal cancer; surgery; recovery.

9.3 Introduction

Colorectal cancer represents a significant disease burden worldwide, with 1.23 million new cases diagnosed in 2008 (International Agency for Research on Cancer (IARC) 2010 online). Almost 60% of new cases occur in developed regions, and colorectal cancer is the third most prevalent cancer in the UK (Office for National Statistics 2010 online). Around two thirds of disease occurs in the colon and one third in the rectum (Cancer Research 2010 online). The most accurate predictor of prognosis is the extent of invasion of tumour through the bowel wall, referred to as T staging (Treanor & Quirke 2007). Five year survival rates for those diagnosed with early stage disease

are over 93%, compared to only 7% of those diagnosed with advanced disease (Gatta et al 1998). Surgery remains the definitive treatment for localised colorectal cancer (Leslie & Steele 2002).

9.4 Literature review

Common symptoms following surgery for colorectal cancer include pain, fatigue and insomnia (Hodgson & Given 2004; Esbensen et al 2006). Bowel symptoms are common including flatus, diarrhoea and constipation (Whynes & Neilson 1997; Pan et al 2010). Although the research indicates a trend towards improved quality of life scores six months following surgery (Ulander 1997; Bailey et al 2006), symptoms of fatigue, insomnia and diarrhoea may persist (Ulander et al 1997). Research suggests the impact of colorectal cancer on quality of life is greatest and most variable within 1-3 years following diagnosis (Ramsey et al 2000). Three years following treatment, symptoms of insomnia, fatigue and altered bowel habits were worse for colorectal cancer patients compared to the general population. Differences in scores were greatest between younger patients (age <60 years), but differences diminished with age (Arndt et al 2006).

Qualitative studies conducted post treatment for colorectal cancer illustrate how symptoms can influence emotional and social functioning. Newly diagnosed patients describe experiences dominated by their physical condition as they pass through a stage of complete dependence and loss of control and dignity (Worster & Holmes 2009). The cancer diagnosis can overwhelm the individual as they experience a loss of control and the disease becomes "omnipresent" (Shaha and Cox 2003). Taylor et al (2010) depict how sixteen individuals experience a loss of body control and disconnection with their body; and recovery requires re-establishment of a

relationship with the body. Emotions of fear, anxiety and vulnerability arise from frequency and urgency of bowel symptoms, particularly faecal incontinence (DeSnoo & Faithfull 2006). Tiredness and weakness impact upon social identity by reducing physical functioning and causing social isolation (Dunn et al 2006). Rozmovits and Ziebland (2004) identify how an individual becomes socially isolated as persistent problems with dietary intake and bowel habits lead to a loss of social confidence. The distress experienced by patients causes the removal of adult identity and "Loss of Adulthood" (Rozmovits & Ziebland 2004).

Frank (1995) describes a shift in the cultural context in which people now experience illness: a time he labels "post-modern". This post modern experience is characterised by technical expertise, demonstrated by the health professional within a complex organisation. Advances in diagnostics and treatment have led to many patients experiencing colorectal cancer as an acute episode; where illness is relatively short lasting and resolves through recovery or death (Rosenfeld 2006). However, the emotional impact of a cancer diagnosis may be associated with mortality (Shaha & Cox 2003) and those newly diagnosed will feel they have been given a death sentence (Comer 2008). Existing research has often adopted a biomedical framework where recovery is measured through sequelae of treatment. There is a relative lack of conceptual consideration of social and cultural meanings associated with colorectal cancer which create an illness experience beyond the immediacy of curative surgery.

9.5 Study aim

The aim of this study is to develop a grounded theory to explain the experience of recovery following surgery for early stage colorectal cancer.

9.6 Methodology

An interpretive approach was chosen to explore participant's experiences as the topic area was relatively unexplored and theoretically undeveloped (Glaser & Strauss 1967). Grounded theory incorporates a symbolic interactionism perspective, where the emphasis is upon the natural world of human behaviour (Chenitz 1986). Grounded theory was chosen to facilitate a longitudinal exploratory study of the social processes and actions of the individual as they recover following surgery.

9.7 Methods

9.7.1 Study setting and sample

The study was conducted at a district general hospital in South East England, UK. Theoretical sampling was employed, where data collection and analysis occur simultaneously, and analysis informs what data to collect next to inform the emerging theory (Glaser & Strauss 1967). The initial sample was determined by the subject area (Chenitz & Swanson 1986), and included those who had completed surgery for tumour of the sigmoid bowel or rectum, and required no adjuvant treatment. Further sampling was determined by the emerging concepts (Goulding 1999), and efforts were made to ensure equal representation of gender and age. Recruitment stopped once theoretical saturation was achieved and no new insights emerge from the data (Glaser & Strauss 1967; Strauss & Corbin 1998). The final sample included 12 (table 1).

9.7.2 Data collection

A longitudinal design was adopted with a semi structured interview at 2 weeks; 3 months; 6 months and 1 year following surgery. Interviews were conducted in the participant's home, between 2007 and 2009. The prompt for the first interview asked the participant to describe their experiences to date. Subsequent interviews were directed to elicit in-depth information about emerging themes and categories (Glaser & Strauss 1967).

9.7.3 Ethical issues

Ethical approval was gained from the Local Research Ethics Committee. Eligible participants were initially approached by the clinical nurse specialist and given an information sheet. Written consent was completed at the first interview, and process consent adopted for the duration of the study by confirming participant agreement at each contact (see Munhall 1991; 2007). Interviews were conducted at the participant's convenience and they were able to have a relative present if they wished. Participants were advised of their right to confidentiality and anonymity, and to withdraw at any time.

Participant No.	Age	Gender	Consultant	Living context	Co-morbidity	Interviews
1	87	M	1	Alone	Arthritis	4
2	83	M	2	With spouse	IBS	2*
3	56	F	1	With spouse	None	4
4	70	F	1	With spouse	Osteoporosis	4
5	80	F	1	Alone	IBS	4
6	81	F	1	With daughter	Diabetes, osteoporosis	4
7	65	M	2	With spouse	None	4
8	76	F	2	With spouse	Arthritis	4
9	69	F	1	With spouse	Diabetes, osteoporosis	4
10	50	M	1	With spouse	None	4
11	68	F	2	With spouse	Diabetes	3**
12	71	M	1	Alone	None	3**

* Participant withdrew after interview 2 due to poor health

** For theoretical sampling purposes, participant 11 & 12 entered the study 3 months after surgery

Table 1: Characteristics of study participants

9.7.4 Data analysis

All interviews were transcribed by the same researcher (NB) to aid recall; to ensure consistency and accuracy of reporting thus strengthening the rigour of the study; and to adhere to ethical principles of confidentiality of the data. A “denaturalized” approach was adopted for transcription, where idiosyncratic elements of pauses and non verbal cues were removed (Oliver et al 2005). Data analysis was conducted according to the steps described by Strauss and Corbin (1990; 1998). Firstly, in open coding each line of text was examined and codes were attributed to individual words or sentences to categorise the data according to their meaning and actions. The code would often directly arise from the data, known as an in vivo code (Charmaz 2006). Emerging codes were compared to existing codes using constant comparative analysis, to examine similarities or differences. Similar codes were grouped together to form categories. Descriptions were given to codes to ensure reliability in the coding strategy, and assist the audit trail. As data analysis progressed, relationships between the categories and subcategories were developed through axial coding (Strauss & Corbin 1990). Finally, the core category was identified as *restoring a sense of wellness*, which had analytic power and pulled the other categories together to form an explanatory whole (Strauss and Corbin 1998). Constant comparative analysis and theoretical sampling continued until each category was saturated and no new properties emerged (Strauss & Corbin 1998).

9.7.5 Rigour

Koch and Harrington (1998) contend the entire research process is reflexive and evaluation criteria may be generated within the project itself, through detailed and contextual writing. Strategies to attend to rigour included one researcher conducting the interviews (NB), regular supervision from an experienced grounded theorist (AA),

the keeping of a reflective researcher's log and field notes, and wide reading of the literature. Memos were used to record reflections on theoretical aspects, data analysis, and the researcher's impressions. Participants own words were used to illustrate the research processes of data analysis and theory development.

9.8 Results

Participants describe recovery in three phases: disrupting the self; repairing the self; and restoring the self. Through inductive analysis, *Restoring a sense of wellness* has emerged as the core category to describe participant's experiences of recovery following surgery for colorectal cancer.

9.8.1 Phase One - Disrupting the self

The conceptual phase *Disrupting the Self* illustrates how personal identity is threatened as the physical body is disrupted by the symptom experience and medical procedures; and hospital practices undermine a sense of autonomy and confidence.

9.8.1.1 Body disruption

Body disruption often begins with the first sign of symptoms which may be acute and specific, such as rectal bleeding. Within a context of apparent health and with no forewarning, these symptoms are abnormal and emphasise body failure from within. More commonly, participants experience insidious symptoms which are non specific, subtle, and harder to quantify:

"I was incredibly tired. I had had a hip replacement the year before and you know how you kind of blame things like that." (4/1)

Alternative explanations are plausible and make it difficult to recognise the seriousness of symptoms. This undermines trust and confidence in body awareness skills.

Pre-operative investigations cause body disruption by inducing intense and uncontrollable bowel evacuation. Nil by mouth protocols disrupt dietary routines, and body disruption is induced by anaesthesia as described by this gentleman:

"I don't know what it did but it almost sent me out of my mind to be honest with you. I didn't know what time of day it was, I couldn't see clearly, I was speaking a load of rubbish, I was vomiting." (12/1)

Altered consciousness and the loss of primary body functions disable this gentleman and place him in a position of vulnerability. He becomes reliant upon health professionals for safety and support. Body disruption highlights the loss of a predictable and trustworthy body, undermining feelings of personal control.

9.8.1.2 Medicalisation within secondary health care

Medicalisation within secondary health care is directed by a prevailing concept of the biomedical model, and interactions are focused around the disease process and treatment. The treatment pathway involves rapid progression through a structured system of technical procedures, which emphasise the urgency and seriousness of their situation. There is *"no time to waste"* (10/1).

"Literally it was, I think I must have been fast tracked, it was so quick". (9/1)

Access to treatment is expedited, and at times the transition between procedures seems impersonal and automated. Participants hand over responsibility for their self management to the health professionals, conceptualised as body handover. Experiences are characterised by immediacy with the physical body and continue up to the point of discharge:

"Well it all happened so fast I didn't even realise I had been in hospital and out again, things were happening so quickly." (4/1)

Rapid transition through treatment and lack of attention to individual needs can weaken the individual's sense of autonomy. Discharge decisions are determined by service demands and participants rarely feel involved, which confirms a focus upon the medicalisation of the illness experience.

9.8.1.3 Emotional disruption

Receiving their diagnosis of cancer creates mixed emotions and some participants experience a moment of time standing still as they attempt to make sense of the news: *"It stops everything."* (3/1). Many have suspected cancer, but confirmation is still a shock: *"It really hasn't sunk in yet."* (7/1); whereas others experience relief that they finally have confirmation of what they suspect: *"It was simply a relief to know what was wrong."* (6/1). Thoughts about cancer can raise fears of a lingering death, filled with disability and pain. Treatments are perceived as unpleasant, uncertain and causing as much disruption as the cancer itself. Cultural and personal views of cancer exert an influence and some participants recall the experiences of their relatives:

"When I knew what I had got, it probably actually was even more frightening because all I could remember was the absolute terrible experience that my mother and myself had gone through." (3/1)

Reviewing past experiences or lay knowledge can trigger negative thoughts and arouse fear. The previous life, which may have been taken for granted, is now gone and the future is uncertain.

9.8.2 Phase Two - Repairing the Self

Following discharge, the individual begins *Repairing the self* through actions and interactions to restore the physical body; regain a sense of confidence and autonomy; and re-establish a sense of personal identity.

9.8.2.1 Body repair

Restoring physical integrity and body function takes time. Participants develop skills of body monitoring by which to assess their progress. The body is "watched" for a period of time to elicit details of how it is functioning and attention is given to the frequency and intensity of experiences and sensations:

"A pain in my stomach which isn't really a pain, it's a sensation which when I bend over or sit down on a chair, in and out of the car, I really get this stabbing feeling."
(9/1)

By comparing experiences, the individual appraises symptoms and interactions. When certain activities appear to exacerbate symptoms and undermine body repair,

the individual has opportunity to manipulate future actions to prevent a recurrence of the symptom. Individuals are keen to restore independence in physical activities as soon as possible to regain autonomy. Actions to accommodate depleted energy include small increments in activity and regular rest periods. These strategies promote attainment of a positive outcome which bolsters feelings of control and confidence.

9.8.2.2 Follow up

Participants describe a follow up schedule based upon a biomedical framework with a priority to monitor for disease recurrence:

"I went back three days after and then 2 weeks after and they didn't want to see me again after that. There was no cancer so there was no reason to go back." (3/4)

When recovery is not as expected, the individual can experience conflict and has to rely on their own interpretation and make decisions accordingly:

"Only wind really and painful wind, and some excruciating wind and I was on the point of ringing and I thought no, I'll just leave it a bit longer and it went. I have been on that point on several occasions, perhaps when this is a bit more than just wind." (3/1)

Regular episodes of abdominal discomfort were at odds with this lady's expectations as the surgeon had informed her: *"I would make a quick recovery because it was only keyhole" (3/1)*. Even when the pain is very severe she feels it is inappropriate to contact the team outside of the prescheduled appointments. Ambiguity and uncertainty regarding what action to take, hinders participants as they begin

reclaiming personal authority. Initiating contact requires proactive behaviour which is difficult if the individual doubts the validity of their concern because of a lack of experience or knowledge.

9.8.2.3 Information

In retrospect, participants feel they have few opportunities in hospital to ask questions and absorb information. Discharge within 48 hours of surgery, whilst recovering from general anaesthetic, adversely affects the ability to retain information. At home, participants feel isolated and spend time reviewing questions to decide if they are important enough to warrant contacting someone.

"So I suppose to have reassurance from someone who's been dealing with telling you, that is perhaps more reassuring than going to the GP who's never seen you before and hasn't had anything to do with the operation." (3/4)

Many information needs are specialised and not perceived as the domain of the GP. Participants highlight that familiarity with a health professional offers reassurance that attention will be given to their personal circumstances. Participants identify areas of unmet need relating to the impact of symptoms on daily life:

"That is one of the things I would have liked some advice on and nobody ever really said. Some sort of diet information, even if it was just a sheet of what you should and shouldn't have." (3/2)

9.8.3 Restoring the self

The final phase of *Restoring the self* is an enduring process in relation to two perspectives: a sense of wellness, or a sense of illness (figure 1). One perspective usually takes precedence, however participants can oscillate between the two; or demonstrate aspects of both perspectives simultaneously. A successful recovery is described as one where a sense of wellness prevails, and illness is relegated to the background.

9.8.3.1 A sense of wellness

A sense of wellness is demonstrated through an awareness and enjoyment of the emotional, spiritual and social aspects of life. Participants demonstrate increasing appreciation and knowledge of their body. Physical recovery is an ongoing process where the past and present are interwoven:

"Physically I have picked up very well. I have bounced back very quickly. I was in a car accident many years ago and remember when I recovered from that. The more you do, the quicker you recover... I went back to work part time. I told the head of department what I had had done and he was very understanding." (10/4)

Advanced body listening skills and introspection are utilised to inform decisions. This gentleman has knowledge and familiarity with his body, illustrated by his ability to predict how his body may react when he returns to work.

Figure 1: Restoring the self: a sense of wellness, a sense of illness

Participants with a sense of wellness do not necessarily have complete restoration of physical health but demonstrate body confidence by engaging in meaningful activities. Failure to progress in the activity is viewed as a positive opportunity to moderate or vary the activity. Expertise is demonstrated when the individual uses this new knowledge to adopt strategies to minimise or avoid risk activities in the future. Participants gain a sense of acceptance of how things are, and of normality. They may adjust their expectations of normality, perhaps by modifying their activity levels or adjusting certain aspects of their diet, but these modifications are not viewed as disruptive. These participants may also express a heightened sense of being alive and an appreciation of the present and future, by acknowledging the past and what they could have lost:

"I make the most of my life while I've got it. I reflect that this time now might not have been mine. I could have been decaying. When you really consider that you might not have a life, you come back and get on with your life. It's made me spend more time with the family and doing things I want to do. In the past I always did what I had to, what I thought I had to do." (10/4)

This gentleman reflects on his past, and that he is fortunate to have the opportunity for a future of personal growth and meaningful activities, rather than simply passing through life. Before illness, his future life would have been one of routine and obligation. With a sense of wellness, participants begin to view the passage of time in relation to their personal calendar, in preference to a treatment calendar. Whilst reaching the first year post surgery is an important milestone, a sense of wellness enables the participant to act as and when they choose as they are not restricted in time by their illness; the illness is predominantly viewed as a past event.

9.8.3.2 A sense of illness

A sense of illness is noted for participants who focus upon the sickness and burden caused by their disease. This sense of illness may be a transient episode in response to a symptom or outpatient appointment; or it may be an overwhelming and all absorbing experience which preoccupies their emotional and physical self. Preoccupation with illness may be in response to persistent symptoms. Symptoms vary in intensity and duration, and defy attempts to exert control over their manifestation. As such, the individual suffers a lack of confidence and becomes preoccupied with habitual body monitoring and comparing:

"Experimentation. See if anything works and some things did and some things didn't. Sometimes I thought it did and then it didn't. It is something I am constantly thinking about it now which I must admit I didn't before." (3/4)

Measures of success are small as this lady attempts to manage her symptoms but repeatedly experiences a relapse. Her failure to break the cycle of dietary intake and nocturnal pain creates feelings of despondency and emphasises her lack of control. Persistent lethargy is also burdensome and several participants complain of being *"tired a lot of the time"* (11/4); or *"just feel sort of weak all over really"* (12/4). This causes frustration and dismay as it negatively impacts on other areas of life, and forces the individual to dwell on their illness. Altered bowel habits are another significant symptom and participants attempt to restore control by adjusting their dietary intake. They conduct detailed and lengthy observations of diet, noting when consumption of certain foods is associated with socially unacceptable behaviours such as passing flatus. Bowel symptoms cause emotional distress and embarrassment, and the individual is tempted to withdraw from activities and social interactions which previously gave pleasure.

Preoccupation with symptoms is enhanced if the symptoms mimic pre diagnosis experiences:

"They have cured me because they have given me another 20 or 30 years of life and whatever niggles and pains, it can't be that, it must be just the settling down so I did hang on to that conversation whenever I felt worried. But at the same time when you've got quite a bit of pain going on you can't help but think oh perhaps they were wrong." (3/4)

This lady explains how her symptom experience impacts upon her emotional health and forces her to adopt a sense of illness. Her pain is the focus of attention which impacts upon her psychosocial health, creating fear and vulnerability, and perpetuating a sense of illness. Regular monitoring of symptoms and adoption of a treatment focused calendar is encouraged by a health system which routinely books consecutive outpatient appointments before the individual has been seen by a doctor. Anticipation of future colonoscopies leads to participants dwelling on a sense of illness as it serves as a regular reminder of their cancer and the potential for recurrence.

9.9 Discussion

9.9.1 Study limitations

This study recruited a small sample from one geographical location, and the grounded theory may therefore reflect the experiences of this specific population. It is feasible that experiences would be different in alternative treatment centres, geographical and socioeconomic locations. A grounded theory emerges as an ever evolving process, rather than a finished product (Glaser & Strauss 1967) and this study requires refinement with other colorectal cancer populations.

Participants describe recovery as a process of *Restoring a sense of wellness*, demonstrated through an awareness and enjoyment of the physical, emotional, spiritual and social aspects of life. Having a sense of wellness exists as a duality with a sense of illness, with movement between the two perspectives, and has conceptual links to the Shifting Perspectives Model of Chronic Illness (Paterson 2001). This duality of perspective is discussed by Doyle (2008) where positive aspects of survivorship including feelings of self improvement, personal growth and an

appreciation of life. In contrast, survivorship can present negative consequences with ongoing physical symptoms resulting from treatment and adverse emotions such as depression. Participants who restore a sense of wellness experience more positive aspects of recovery and either have less, or are more able to manage negative consequences.

Survivorship as a concept has evolved to reflect scientific, social and cultural change (Leigh 2001), and is no longer simply defined in terms of disease free intervals. Survivorship is viewed as a dynamic continuum from diagnosis until death (Feuerstein 2007). The literature on survivorship has conceptual similarities to restoring a sense of wellness. Little et al (1998) describe cancer survivorship as a state of liminality; a space between two places. Survivors pass through the space of illness but do not return to the normal world, because this world is no longer the same as it was before the illness (Little et al 2000). This sense of transition is evident for participants who moved through a stage of acute illness, and returned home as an individual recovering from colorectal cancer. Their life at home is different as a consequence of their illness. The diagnosis of cancer challenges prior plans for the future, which have to be temporarily halted, modified or discarded. The transitory nature of life leads them to question their beliefs and attitudes towards life (Shaha & Cox 2003). In restoring a sense of wellness, participants adapt expectations and behaviours to their new life situation. Focusing on the future provides forward movement, and restores a sense of purpose and meaning to life. Their sense of arrested temporality experienced at the point of diagnosis does not last and plans for the future begin to re-merge (Breaden 1997). Little et al (2000) call this reorientation, where the individual comes to terms with the illness by understanding the limitations imposed, and reconstructing their life to give meaning beyond the facts of the illness. Restoring a sense of wellness involves participants assessing and accepting

limitations within recovery. This is noted with regards to fatigue and altered bowel habits as some participants become adept at assessing and monitoring these symptoms. They appreciate factors which exacerbate their experiences, and develop strategies to enable them to manage the symptoms and continue with desirable activities. Having less complex expectations for recovery may also be beneficial as those with a "take for granted attitude" have a smoother recovery (Winterling et al 2009). Studies suggest that between 20% and 30% of survivors have ongoing health problems, resulting in substantial negative social and economic effects on individuals (Corner 2008). Restoring a sense of wellness includes an element of hope: participants are optimistic that symptoms will subside, or that they will gain confidence and mastery in managing the symptoms. Ramfelt et al (2002) suggest a sense of hope offers some protection against despair. The experience of survivorship is one that deals with "the body as a house of suspicion" (Breaden 1997). Participants work to put symptoms into perspective and categorise tiredness or pain as side effects of surgery, rather than an indicator of disease recurrence.

In contrast, persistent symptoms cause some individuals to remain focused upon their illness, within a sense of illness. Symptoms may be viewed as threatening and indicative of disease recurrence, particularly if they mimic pre diagnosis experiences. Fatigue is described as a physical, social and emotional experience; associated with the curtailment of activity, reduced feelings of control and a sense of illness. Fatigue challenges the ability to perform activities with ease or spontaneity (Leidy & Haase 1999). Unpredictable bowel actions are also common, and cause a degree of uncertainty and emphasise a loss of control; as noted by Galloway and Graydon (1996). Participants engage in self care strategies of monitoring and modifying dietary intake to ascertain association between food products and symptoms (also noted by Pan et al 2010). Participants believe high fibre foods are culpable in

causing diarrhoea or flatus and so are avoided. Smaller meal portions and eating at regular intervals are other strategies tried by participants; also reported by Campbell et al (2001) and Kidd et al (2008). The loss of control of the body is unfamiliar to some and creates concern and anxiety, as found by MacDonald (1988). Bodily repair has to be attended to as it limits or interferes with other physical and social activities (Kelly and Field 1996). Participants engage in body monitoring and comparing to evaluate physical recovery. Achieving control over physical symptoms and the body is important for several reasons. Firstly, physical suffering will lead to emotional suffering because personal identity becomes what it is through the body, and the self is affected by what happens to the body (Corbin 2003). Secondly, failure to control the body causes uncertainty and a sense of unpredictability.

Health professionals may underestimate either the prevalence or the impact of physical symptoms (Volgelzang 1997). Kozachik and Bandeen-Roche (2008) question whether cancer and treatment related symptoms in older people are sufficiently managed. The findings of this study would suggest that on occasion, participants dismiss their needs as a normative experience of ageing and therefore do not seek assistance. This finding is also supported by Pound et al (1998). Kralik et al (2004) describes self management as a dynamic, active process where the individual learns, trials, and explores the boundaries caused by their illness. For participants in this study, self management becomes a focus for time and energy to review, reflect, monitor, and experiment with various actions.

9.10 Conclusion

The grounded theory has emerged from the data and illustrates how colorectal cancer and treatment disrupt a sense of self identity. Recovery is an ongoing

process where the individual is concerned with restoring a sense of wellness. Recovery takes time and energy, particularly when the individual is at home and in relative isolation from health professionals. Clear opportunities exist for nurses to provide information and support to facilitate the individual in their progress towards achieving a sense of wellness.

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9.12 Evidence of submission

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CHAPTER 10: POLICY REVIEW IN SPECIALIST FIELD

Better Information, better choices, better health: A policy analysis

10.1 Introduction

This policy review will consider a policy published in 2004 which has direct relevance to the specialist area of practice and research of the author. The author works as an independent nurse researcher, for a cancer charity. Work undertaken to date for this charity has included evaluation of various information and support services, including those based within primary, secondary and tertiary health care settings. The key emphasis of the evaluation work has been focused upon how these services have been developed, and how they aim to meet the information and support needs of the users. Alongside this, a secondary aim has been to consider the various models of service provision and how to enhance the skills of those professionals providing the service.

10.2 What is Public Policy?

The term 'policy' is widely used and cited in government and legislative publications, academic literature, the media and the public domain. A review of the usages of the term policy reveals no simple definition, rather a 'recipe' of common uses. Hogwood and Gunn (1984) discuss possible categories of policy including policy as: a label for a field of activity; an expression of general purpose or desired state of affairs; specific proposals; decisions of government; formal authorisation; a programme; an output;

an outcome; a theory or model; a process. Colebatch (1998: 1) describes policy within the current political practice as “a prior statement of actions and commitments of future government in respect of some area of activity”. As such, policy is viewed as an outcome of an action taken by government.

Public policy is seen by many to be concerned with the decisions and actions of government and the public sector (Dye 1972, Considine 1994). “Any public policy is subjectively defined by an observer as being such and is usually perceived as comprising a series of patterns of related decisions to which many circumstances and personal, group, and organisational influences may have contributed” (Hogwood and Gunn 1984: 24). The incorporation of multiple and related decisions, and the involvement of various stakeholders within this definition are key statements. Policy must be understood as a dynamic and evolutionary process that is influenced by a series of policy drivers, that seeks to define broad goals and specific mechanisms, and that it is mediated and interpreted through different institutions that take actions to implement policy (Blaikie and Soussan 2001).

10.2.1 Policy Analysis

Many tools have been developed to assist in the process of policy analysis. However many of these tools are quite abstract in their approach and whilst offering a method for providing a general understanding of the policy processes, they are more difficult to apply in specific policy settings. Similarly, many tools only consider part of the policy process rather than a comprehensive analysis of the whole process. Colebatch (1998) states that policy analysis cannot be viewed as separate from the policy making process. As with the two predominant views of the policy process; the Rational Model and the Structured Interactive Model, two dominant approaches to policy analysis exist. Blaikie and Soussan (2001) succinctly distinguish between

policy analysis which is 'state-centred' and that which is 'society-centred'. State-centred policy analysis aims to improve policy and policy making and is based upon a set of rationalistic assumptions, which takes little account of external factors and influences. 'Society-centred' analysis assists in the understanding of how policy is made and attempts to capture the different influences and perspectives which exist within the policy process.

Collins et al (1999) state that attention must be given to the nature of the policy context and that this serves to explain why issues are on the political agenda. Failure to recognise or interpret these may result in policies which fail to address the underlying problems facing society and health services. Blaikie and Soussan (2001) propose six basic steps for policy process analysis including: key policy milestones; political and governance contexts; key policy issues; policy development process; outputs, outcomes and impacts; the future. These six steps are then structured into a dynamic analytical framework which importantly includes both policy development and policy implementation. The steps have a logical progression and clarity, but attention is also given to the elements of contingency and agency inherent in the 'real world'. Blaikie and Soussan (2001) continue to describe the main elements of the policy process model as including; influences; agents of change or resistance; policy drivers; macro policy and policy content; communication and dissemination; implementation. These elements will be utilised within this policy analysis.

The author conducted a systematic search of various sources of information including nursing, medical, sociological, political and economic databases; the internet; governmental and department of health databases; and the media. A variety of key words were used throughout these searches including policy; analysis; health; public health; information; health service provision; partnership. Subsequent sources of

information were found following review of the primary sources, including recommended texts, internet sites; and patient and user forums.

10.3 The Choice of Policy

In undertaking this policy analysis, consideration was given to several issues. Firstly the policy chosen had to fulfil various criteria including that the policy was directed towards issues within the health sector and that the policy had been developed with clear objectives and aims. The policy was also required to have clear actions for implementation. The policy was required to be applicable to the author's area of speciality i.e. cancer care and information provision, and recently produced. This would ensure that the analysis of the policy would have direct implications and applicability to the current and future working of the author. The policy chosen fulfilled these criteria and was specifically chosen as the policy outlines a strategy which potentially has far reaching implications for future health service provision concerning the information needs and provision for health care users.

10.3.1 Outline and Description of the Policy Paper

This section will outline the key components of the policy, describing the identified need for this policy, and the principles and aims identified within the policy. A brief description of the key components of the policy will be given, and how the strategy will be delivered.

10.3.1.1   The Policy: Better information, better choices, better health (DH 2004a)

The policy begins by outlining the historical background of health service provision as directed by the Labour Government. Key features include the development of a modern NHS, which is responsive to the changing health needs of the population during the 21st century. The policy then continues to highlight the role of information provision within this modern NHS, by ensuring information is an integral part of health care. A crucial statement relates to the development of 'partnerships' between the users of health care services and health care providers. Information provision is seen as essential to foster and develop this 'partnership'.

10.3.1.2   The Strategy

The strategy outlined within the policy is a three year programme of action, at a national and local level, designed to improve equitable access to quality information which people need and want to exercise choices about their personal health and healthcare.

To this end, the strategy is underpinned by four principles that people should:

- Have access to accurate, high quality, comprehensive information delivered in the way they want;
- Have their personal information needs considered and discussed at every contact with healthcare professionals;
- Receive as much support as they want to access and understand information;
- Be empowered to ask questions and be involved as far as they want in making decisions and how any risks can be mitigated.

The strategy identifies five areas where change is required and then outlines how the strategy will be delivered, incorporating the roles of stakeholder organisations. These five areas include:

- Information for all: improving access to information.
- Quality signposting: getting the right information.
- Personalised information: strengthening the relationship between patient and professional.
- Organisation roles and responsibilities.
- Improve the promotion of health and health services: making communications central to how we care for people.

To conclude, the strategy outlines five areas which will serve as checklists for action and include:

- Supporting service providers.
- Empowering people.
- Developing professional standards.
- Local activities.
- Monitoring arrangements.

As outlined previously, the six elements of policy analysis described by Blaikie and Soussan (2001) will now be considered with specific relevance to the chosen policy.

10.4 Influences for this policy development

Many factors have influenced the development of this policy. Key influences within the policy analysis process include discuss key policy milestones (including policy

heritage, legal frameworks and specific events) and changing political and governance contexts (including social, political, economic contexts; institutional influences; donor and external influences; innovations and knowledge) (Blaikie & Soussan 2001).

10.4.1 Key Policy Milestones

10.4.1.1 Policy Heritage

Whilst the Conservative Government were in office, public services were run in a very similar way to the private sector. Many argued that the public sector was dominated by producer interests (the bureaucrats and various ranks of other employees) and that there was little control or regulation of these producers in terms of market forces, unlike the private sector (Emmerich 2003). This resulted in public services being neither efficient in terms of resources, nor responsive to the consumer needs. As a solution, public services were fragmented and quasi market forces were introduced. This included the introduction of a purchaser-provider divide within organisations and the development of performance targets and incentives.

The Labour Government ideology, which focuses on the 'Third Way', was in some part a response to the previous 18 years of 'Thatcherism' (Klein 2001). Key words and phrases which abound in discussions of the Third Way include community, partnership and strong government. "Rights go hand in hand with responsibility: 'an inclusive society imposes duties on individuals and parents as well as on society as a whole' (Klein 2001). To achieve these ideals, the Government stated that radical modernisation was required. After the appointment of the Labour government in 1997, their emerging public sector management agenda incorporated two key components: the improvement in performance measures to make them a more effective means of improving standards and efficiency; and the reform of markets so

they involved a mix of partnership and competition (Cutler & Waine 2000). This 'new thinking' was based upon the idea that the traditional organisational form of the public sector, hierarchical bureaucracy, was inefficient and that the introduction of market mechanisms would enhance the efficiency of public service delivery (Mills 1998: 5). Specific changes included the abolition of the internal market between General Practitioner's (GP's) and hospitals, and the contracting out of public services to the private sector became more concerned with securing the best outcome rather than on the process by which it was achieved (Emmerich 2003).

10.4.1.2 The National Health Service

Similar themes can be found throughout many white papers produced by the Labour government with relation to the National Health Service (NHS). The first critical white paper entitled 'The NHS Plan: a plan for investment, a plan for reform' was produced in 2000 (DH 2000b). The opening statement comments that "The purpose and vision of this NHS Plan is to give the people of Britain a health service fit for the 21st century: a health service designed around the patient." The concept of developing quality services was seen as crucial to the rejuvenation of the health care system. Key objectives for the NHS reform related to an increase in financial resources and "a new system of earned autonomy will devolve power from the Government to the local health service as modernisation takes hold" (DH 2000b). This concept of decentralisation is fundamental to the 'third way' philosophy. To continue this theme, key initiatives were also made which related to giving more autonomy and power to the public to actively involve them in making choices and decisions about their own health. A plethora of publications ensued, each one advocating greater involvement and responsibility to the public for monitoring and enhancing their health and use of health services (DH 2000a; DH 2001a; DH 2001b; DH 2004a).

A central theme running through all the reports and policies produced during the first eight years of the Labour Government has been the idea of 'partnership'. A failing of the NHS, still operating in a 1940's system, was perceived to be an over-centralisation of power which served to disempower patients (DH 2000a). The wide spread advocacy of 'partnerships' as an essential requisite of health service reform has continued, despite a lack of evidence to support the view that partnerships produce successful outcomes for staff, users, financial sponsors and other stakeholders (Dowling et al 2004). This ethos of partnership is strongly included within the Better Information Policy as demonstrated by the following quote "Modern public services are built on effective partnerships...Better health care outcomes are achieved when this partnership is at its strongest – when both patient and health professional share in making decisions about treatment and care" (DH 2004a: 1).

10.4.1.3 Legal Frameworks

Two key legislations which have applicability to this policy include the Human Rights Act 1998 (HRA) and the Data Protection Act 1998 (DPA). Within the United Kingdom, the HRA specifically legislates for equality that outlaws discrimination and provides a mechanism for individuals to lodge complaints when they experience unlawful discrimination. There is currently direct legislation dealing with discrimination on the grounds of sex, race and disability which applies within many services, including health. The DPA states that all citizens are entitled to see all information relating to their physical or mental health which has been recorded by or on behalf of a health professional in connection with their care. This right of access covers both the NHS and private medical records, with no time limit for access.

The Department of Health publication 'Guidance on developing local communication support services and strategies' cite ten legislations and policy frameworks which

must be considered by commissioners and those involved in developing services (DH 2004b). These include, amongst others, reference to the Health and Social Care Act (2001), Race Relations Act (1976, 2000), and the Disability Discrimination Act (1995). A key recommendation of this report was that commissioners must engage, consult and involve local communities in the planning, developing and evaluating of services. The report 'Building on the best: Choice responsiveness and equity in the NHS' emphasised that the NHS needs to "work at ensuring choices and services genuinely reach everyone, including the most disadvantaged and marginalised groups" (DH 2003). Consultations were conducted with various stakeholders and patients during the development of this policy. One key outcome from these consultations was that people said they wanted improvements in the quality and accessibility of information as a prerequisite to making information choices about their health and health care (DH 2003). The policy 'Better Information' cites this policy as a direct precursor, and was developed to address this issue raised within the consultation process.

10.4.1.4 Specific Events

Several high profile media cases may also have potentially served as influences for this policy. Following the publication of the Lord Phillips report into the BSE crisis, the Government admitted a lack of openness about the possible risks of BSE (BBC 2001). The Agriculture Minister Nick Brown responded to the report, saying "Firstly, we must trust the public," he said. "If there is scientific advice available to the government on which decisions are to be made, that scientific advice must be put into the public domain". He continued to say "We are going to set out to explain risk better, but keeping secrets is not the way to do it. We need to have a culture of openness and the advice that comes to government has to be assessed independently" (BBC 2001). Similar findings relating to the way information was

provided within the public domain were also identified in the Bristol Babies Inquiry. This report criticised the hospital and professionals for the secrecy surrounding the care and treatment of many babies requiring heart surgery. Key recommendations from the report included: keeping patients informed about care and treatment, with better communication and support; information, on how trusts and doctors and services within them, perform compared to others should be available to the public; the public should be more involved in the running of the NHS (BBC 2003).

These two high profile cases received much attention in the media and served to raise the profile of how information about health care and services were provided to the general public. They fuelled the ongoing demand from many public and user groups to be more involved in daily decisions about health services, both from the perspective of providing services and also to fully inform the population about issues relating to their health. A review of how the media reported a set of NHS performance indicators found that on the whole the newspapers had made a reasonable attempt to convey an overall assessment of how the NHS was doing (Appleby & Bell 2000). The review focused on eight major British newspapers and found variations in the manner in which figures were reported. In particular, only one newspaper mentioned the statistical aspect of the indicators in that there is a degree of uncertainty surrounding the figures. This same newspaper presented the confidence interval for the data, but failed to mention how to interpret any overlaps between intervals. The authors conclude that newspapers are faced with the dilemma as to whether to oversimplify the figures to make them understandable and presentable to the public, thereby risking distorting the data; or whether to present the data 'as is' and risk confusing people. A survey of public health experts and policy-makers also raised this criticism of the media inaccurately or incompletely reporting complex data (Harrabin et al 2003). Those interviewed believed that the media exert a strong influence over the perceptions and knowledge of the public and therefore

had a responsibility to report accurate information. The policy 'Better Information' acknowledges that the public often obtain their information from the media however there is no mention of how this aspect of information provision should be regulated or could be influenced.

10.4.2 Political and Governance Context

10.4.2.1 Social, Political and Economic Context

During Labour's first term in office, fundamental changes were made within central and local Government. Public Service Agreements were introduced during Labour's first term which required government ministers to be accountable directly, rather than the agencies they controlled, for the aims, delivery and achievement of departmental targets. Resource allocation was fixed for three years and a key aim of the agreements was to enable departments to manage their own resources rather than applying to the Treasury for additional funds (Emmerich 2003). Local Public Service Agreements (LPSA) were piloted and then rolled out to local authorities from 2000. The overall aim of LPSAs was to improve the delivery of local public services by focusing on targeted outcomes with support from Government. John Prescott, Deputy Prime Minister, states in the White Paper 'Modern local government: in touch with the people', "Modern councils should be in touch with the people, provide high quality services and give vision and leadership for local communities. Modern local government plays a vital role in improving the quality of people's lives". (Office of Deputy Prime Minister 1998). These changes began a process of devolving central held responsibility. Ministers and other officials were made accountable for the quality and efficiency of the services they provide. These services had to be provided where they were needed, and had to take account of the users and recipients of these services.

The NHS Improvement Plan: putting people at the heart of public services cite an increased budget for the NHS during Labour's first seven years in office, with a budget of £67.4 billion and an average spending per head of population of £1,345 (DH 2004d). However this extra spending is given with the proviso of increased performance, a stronger emphasis on quality and safety, alongside a continuing focus of providing services efficiently, fairly and in a personal way. The report states that by 2008, patients will be able to choose from a growing range of independent providers, including the independent sector. These providers will be monitored and inspected by the Healthcare Commission to ensure high-quality care for patients. The report also outlines how information systems will be put in place to enable patients to make these choices, using a variety of methods including electronic booking, NHS Direct, NHS Direct Online and NHS Digital Television (DH 2004d). The Wanless Report (2002) identifies the most significant determinant of future health costs in a review of long term health care trends as the extent to which the public are engaged in modifying their own health-related behaviours. This finding has served as a strong influence for the changing social focus upon people acting in partnership with health care providers, and taking more personal responsibility for their health and behaviour. The policy 'Better Information' makes explicit the relationship between providing clear and accurate information, in a manner which is tailored to the individual's needs, relating to public health issues such as disease prevention and healthy lifestyle behaviours. The implicit argument behind this is that by providing individuals with information and choice, they will then take a more active responsibility for their own health and lifestyle behaviours.

10.4.2.2 Institutional Influences

Institutional influences include the structure and capability of formal institutions: central government agencies, local government, the private sector, political parties and organised religion. With relation to this policy analysis, government agency influences have already been discussed. The private health care sector may also have an influence over the development and provision of health services. Changes which are taking place between the public and private health care sector may lead to a weakening of the power of the public sector to influence the direction and delivery of public health care services in the future (Lethbridge 2002). One of the most influential changes in the public and private sector relationship relates to public-private partnerships (PPP). These partnerships involve the NHS contracting a variety of goods or services from the private sector. Within the UK, the aim of Private Finance Initiatives (PFI) is for the private sector to provide capital to build a new hospital, which is then leased to the NHS for 20 years or longer. Over time, it is likely that these private sector providers will have increasing control and authority over the direction and development of health services. The Government's rationale for involving the private sector relates to the transferable skills and resources to benefit the public sector, including commercial incentives leading to increased efficiency; a focus on customer requirements; new and innovative approaches; business and management expertise (Treasury Department 2003). One significant outcome of these public and private partnerships may be the process of formalising links and partnerships between organisations. Whilst these links already exist, over time they may become more institutionalised and therefore have a greater impact upon future policy. A positive outcome of these partnerships may well be the combination of strengths and skills to meet health service needs, however consideration must also be given to the complex issues such as the different and sometimes conflicting

interests and objectives of the different players, working within different governance structures (Nishtar 2004).

10.4.2.3 Donor and External Influences

Key donor and external influences with relation to the influences for this policy include voluntary health service providers, charities, and also patient and user representative forums. Many voluntary and charity organisations provide additional services to that provided by the NHS. With specific relation to cancer, examples include various information services such as BACUP and the Macmillan Cancer Line. The Labour Government has no ideological preference for who should deliver public services, instead that decision should be made based upon who can provide services most effectively for the resources available, including the public sector, private sector and voluntary and community sector (Blackmore 2005). Blackmore continues to cite a statement from the Prime Minister in October 2001: ""In developing greater choice of provider, the private and voluntary sectors can play a role. Contrary to myth no-one has ever suggested they are the answer. Or that they should replace public services. But where they can improve public services, nothing should stand in their way."

The Government have stipulated that health service providers are also required to actively involve the public in the planning and development of future services (DH 2000b; DH 2001a; DH 2001b; DH 2004a). At a clinical level, there is increasing focus on user views being sought about services, for example the Patient and Public Involvement Forums, and the development of user-led management programmes to enhance people's ability to self manage their own health care (DH 2001a). At a strategic level, users are being encouraged to participate in the planning and development of services (DH 2000a). The Community Care Needs Assessment Project comment that users should be involved in setting the agenda, not just

respond to what has been decided by service providers. Consumer involvement is believed to result in health care of a greater quality and clinical relevance (Boote et al 2002), and that health services have to develop partnerships at all levels of care in order to evaluate the effectiveness of services from a user perspective (Maslin-Prothero 2003). Many user groups have focused on the danger of 'tokenistic' user involvement which can result from health services involving users as quickly as possible to fulfil contractual agreements. As a result, scant attention is paid to the selection and recruitment of users. Anderson et al (2002) found one of the major challenges for lay people was to gain respect and authority as full members of Trust boards. Whilst most were welcomed by the boards, they did not always have authority with regard to decisions and discussions. They continue to say that involving voluntary and community sector organisations can add 'weight' to user involvement "as collective voices of patient and public interests".

The 'Better Information' policy comments that a variety of key stakeholders, including those from the community and voluntary sector, and patient organisations were consulted during the development of the strategy (DH 2004a: 32). The policy also outlines how partnerships between the Department of Health, voluntary sector organisations, and regulatory bodies will take responsibility for setting up an information accreditation scheme (DH 2004a: 30). Many voluntary agencies have provided valuable services for imparting information to the public however to date there has been little co-ordination of these services. This has resulted in a somewhat 'piecemeal' approach to information provision and resources. For the public and particularly those who are currently receiving services from health care, the idea of finding and accessing information can be daunting. To regulate and develop a more systematic method for information provision is a main aim of this policy and has been directly influenced by existing services.

10.4.2.4 Innovations and Technology

The increasing availability and use of technological advancements, including the internet, the media and digital services, has resulted in a wide variety of mechanisms by which to provide and impart information to the public. The e-government unit has been briefed with ensuring that information technology (IT) is a fundamental part of all government, so that better, more efficient public services can be provided. The role of IT is seen as essential to provide services that are prompt, convenient, responsive and of the highest quality, and are tailored around the individual to give people the services they expect (Watmore 2004). One aim for the unit is to present one joined-up Government service to a citizen, regardless of which agencies are involved behind the scene. With specific relation to 'Better Information', technological advances have had a significant influence on the policy development and the mechanisms for implementation. Examples include the NHS Direct Interactive, Health Direct and NHS Direct Online (DH 2004a: 12).

10.4.3 Conclusion

The influences outlined above have had a major impact upon the development of the policy 'Better Information'. Of particular relevance is the impact of the Labour Government and their political ideology. The 'third way' adheres to the principle of decentralisation of power and responsibility, and also that health providers and recipients should be equal partners in the health care system. The policy has been developed to enable citizens to access reliable and appropriate information, thereby empowering them to make decisions about their own health. Quite simply, the economics of providing a health service to all, free at the point of access and equitable, cannot be sustained at the current rate. Future demands for services are likely to rise, particularly with an ageing population and therefore future health plans

have to include an onus on individuals to accept some personal responsibility for their lifestyle and health.

10.5 Agents of Change or Resistance

The influences outlined above act upon strategically placed individuals and institutions who then become the agents of change or resistance (Blaikie & Soussan 2001). With relation to 'Better Information' these include both institutions such as NHS Trusts, PCT's, individual members of the workforce, other stakeholders such as voluntary and community organisations, and individual citizens. In a summary of the key conditions for the management of change, Coventry University state that "change agents must involve, consult and inform all concerned colleagues about their work. Effective change requires effective communication at all levels" (Coventry 2005). Evaluations of change agents to date have predominantly been based upon social intervention theory which suggests that local habit, socially accepted norms of appropriateness and peer acceptance are powerful motivators of change (DoH 2005). However the Government recognise that there is a need for rigorous evaluation of the effectiveness and cost effectiveness of change agents (DoH 2005). The Change Centre suggest a philosophy that shifts emphasis from static theorising towards 'doing' and 'risk taking' (Change Centre 2003). They comment that there is a need to move from planning and telling practitioners what to do, towards building relationships which requires an understanding of the role of all stakeholders in sustaining social values and the infrastructures that will support practitioners. The 'Better Information' policy recognises that service providers need to be supported to achieve the actions for the policy. A key area for action relates to the incorporation of communication and information provision techniques to the forefront of training for all health care workers (DH 2004a: 28). The policy stresses that this will require a long

term cultural change, which will require the support of relevant regulatory bodies. Many professional regulatory bodies already include specific statements concerning the role of professionals in providing information to patients such as the following excerpt from the Nursing and Midwifery Council Code of Conduct "All patients and clients have a right to receive information about their condition. You must be sensitive to their needs and respect the wishes of those who refuse or are unable to receive information about their condition. Information should be accurate, truthful and presented in such a way as to make it easily understood" (NMC 2004). Whilst most stakeholders would support the strategy outlined within the policy, financial constraints are a major consideration for many institutional organisations and therefore may act as a resistor to any implementation of the policy. This will be discussed further when considering implementation of the policy.

10.6 Macro Policy and Policy Content

Macro policy is the outcome of the policy development process and results in the production of a policy document. An examination of the specific mechanisms through which the policy will be implemented is a key stage of the policy analysis process. These mechanisms usually include general goals and priorities and two forms of actions: those of state agencies; and those of non-state institutions (Blaikie & Soussan 2001). The Better Information Policy identifies several key stakeholders who will play a role in shaping and delivering the actions set out in the strategy. These include both state and non-state institutions.

10.6.1 Actions of State Agencies

A critical issue that needs to be examined is the extent to which the mandates in the policy are then followed by changes to institutional structures and capabilities, budget flows and the legal framework in which agencies work. At this stage there is a reflexive relationship between policy and existing institutions and their mandates (Blaikie & Soussan 2001). The policy 'Better Information' outlines how information provision is a priority within the National Standards, Local Action, the Health and Social Care Standards and Planning Framework for 2005/6 – 2007/8 (Domain 4 – Patient Focus) (DH 2004a: 4). These standards outline that healthcare organisations must have systems in place to ensure patients and their relatives have suitable and accessible information about, and clear access to, procedures to register formal complaints. Health care organisations must make information available to patients and the public on their services, and that the provision of this information must be at a time and method determined by the patient/ relative. In addition, the NHS Plan explicitly outlines where and how patients must be involved in the development of services (DH 2000b). The plan states that the NHS must be responsive to the varying needs of individuals within communities, irrespective of gender, ethnicity, age, religion amongst other characteristics. The Health and Social Care Bill (2000) outlined the Government's programme of investment and reform in the NHS, putting patients at the heart of a modernised service (United Kingdom Parliament 2000). This bill states that the NHS has a duty to consult with and involve the public on the planning and delivery of local health services, with mechanisms placing patients and public in the driving seat. The Bill provides a statutory duty on all NHS organisations to: consult with and involve patients and the public; to set up statutory, independent Patient Forums; appoint new independent support for patients complaints; be scrutinised by elected local councillors.

The introduction of the policy 'Better Information' supplements and builds on many of these existing Government and agency policies. As such, it does not change the legal framework within which many institutions already operate. However, there are significant changes to the potential resource and budget implications for many institutions. The policy states that the setting up of information provision should be seen as an integral core component of services, rather than an 'add on'. Therefore, the implication is that extra resources should not be required, rather they should be ringfenced within existing budgets and resources. This may have a far reaching effect for this policy during the implementation stage.

10.6.2 Actions of Non- state institutions

Regulations are set within the policy which aim to change the behaviour of non-state institutions including the media, voluntary and community based organisations, and the general public. The policy recognises that the public obtain their information from a variety of sources and that people often value independent information (DH 2004a). Therefore the involvement of non-state institutions is essential to the policy process and implementation of the actions. The policy advocates an active partnership between these non-state institutions and the NHS. The policy recommends the development of a national information commissioning and prioritisation framework. The main benefit of this would be "to bring clarity to who is responsible for doing what in terms of designing, disseminating and delivering information at both national and local levels. This would eliminate local duplication of information which can be made available nationally, and through clear commissioning arrangements will maximise the contribution VCS organisations can make". (DH 2004a: 21).

10.7 Communication and Dissemination

Following the formalisation of the policy, consideration needs to be given as to how the policy will be communicated and disseminated. Lack of attention to this process can result in a failing of the adoption and utilisation of the policy (Blaikie & Soussan 2001).

The Better Information policy has a circulation list of Local Authority Chief Executives, Directors of Social Services, non departmental public bodies, voluntary organisations and arms length bodies. The target audience is much broader, including various medical and nursing bodies and professionals, allied health professionals, community and primary care professionals, and communication leads. The report is freely available on the Department of Health website. Blaikie and Soussan (2001) state this stage is a key to the effectiveness of the policy but is often not recognised. It is at this stage that the vertical and horizontal dimensions of the policy process outlined by Colebatch (1998) play a significant role. It is only by recognising that the different dimensions involve different stakeholders, that a policy can be effectively communicated. As this policy has been so recently introduced, there is no evidence to date as to how the policy has been disseminated throughout these dimensions.

10.8 Implementation

Once the specific mechanisms for action have been specified in the macro policy, the process of implementation can begin. A critical issue is how the policy is interpreted by the implementing agencies. Blaikie and Soussan (2001) identify six broad categories of implementation agencies: lead agency(s); other state agencies; private sector; non government organisations; civil society; and individuals. They continue to identify 3 stages for each agency with regard to the direct effects of the policy: interpretation of policy; actions; outcomes. Interpretation of the policy is influenced

by the institutional culture, capabilities, priorities and resources. Actions reflect a series of choices on what to do that reflects the policy interpretation and the resources and capabilities of the institution. Finally the outcomes relate to changes to patterns of resource management and changes to availability of resource flows. These outcomes can be less than or different to those intended if implementation is not effective. Colebatch (1998) comments that a widely acknowledged problem with implementation is that the actions required do not work at 'ground level', and the outcomes are likely to be different from the original stated intentions. To address this issue, the Government commissioned a discussion paper to encourage more rigorous thinking about delivery issues and to specifically focus upon what can be done to assist those on the frontline to achieve better implementation and results (Performance Innovation Unit 2001). The paper showed that delivery of public services is dependent upon the actions of people and institutions that cannot always be directly controlled by central government, departments and agencies. This view is supported by Watt et al (2005) who comment that policy as a tool for practice change must address the organisational, professional and social contexts within which the policy is to be implemented.

The policy 'Better Information' builds upon the ethos of a partnership between differing health service providers, by involving private sector and voluntary group sector representatives. Explicit actions are outlined within the policy to develop these partnerships. An example is the collaboration between NHS Direct and Bowne Global Solutions to provide a national translation and interpretation service. Another example relates to the partnership between the voluntary sector organisations, regulatory bodies and the Department of Health in setting up an information accreditation scheme (DH 2004a). The Department of Health, and subsidiary departments are identified as the lead for all the activities outlined within the policy.

Listings are then provided of which agencies will act in partnership with these leads to implement the policy actions.

The process of implementation for the policy `Better Information` will be considered with specific reference to one area for change: Information for all – improving access to information.

The policy bases the strategy for improving access to information on the principle of equity. The policy states that equity is understood to mean providing a universal service, and that current health services do not provide an equitable information service to users and the public. A major gap in the evidence relating to health inequalities is that dimensions of social position and difference, such as ethnicity, gender, disability etc., are under developed empirically and theoretically (Graham & Kelly 2004). Additionally, the distinction between the determinants of health and the determinants of inequalities in health is rarely explicit and therefore has little impact upon the policy making process. The `Better Information` policy states that to achieve true equity in providing information to the people, the information must be personalised and directly relevant to the individual. However the question remains whether those who potentially stand to benefit from the policy, i.e. those who are disadvantaged, are the ones who are able to access the services they need.

10.8.1 Three areas for improving access to information.

10.8.1.1 Translation and Interpreting Service

The policy makes little reference to specific inequalities, with the exception of ethnicity. The policy comments that language barriers are one of the most fundamental problems affecting the communication and distribution of information.

To address this issue the policy outlines the development of a universal translation and interpreting service through a partnership between NHS Direct and a private sector organisation (p10). The policy quotes the report 'Health Literacy' (Sihota & Lennard 2004), however makes no explicit mention of how inequalities relating to literacy levels will be addressed.

10.8.1.2 Community Based Navigators

The policy continues to talk of 'community based navigators' who will assist the public in finding information and making choices about their health. It is not explicitly clear what form these navigators will take although the policy states the Department of Health will support local PCT's to decide with local partners how best to enhance face to face community based support. The policy mentions health advocates, patient care advisors and the Expert Patient Programme which successfully support people in making decisions about health care. In addition 'Choosing Health' outlines proposals for NHS-accredited community based health trainers. The issue of where and how people can access information is very important. Even if information is widely available, attention must be given on how to enable and encourage people to access this information. The idea that by providing a service will then result in people accessing and using that service is not so clear. The provision of community based navigators, assuming they are correctly located within the local communities and accessible, does not guarantee that people will access them. It is likely that the majority of people, particularly those who are receiving other forms of health services, will choose to utilise these 'navigators' however, the issue of whether this service will be equitable is not fully addressed. The argument remains that those who choose not to access services may in fact be the most disadvantaged in other ways, such as

ethnicity, socio-economic groups etc, and may therefore benefit the most from the service.

10.8.1.3 Making High Quality Information Available to all Nationally

This section incorporates five areas for development. These include various methods of providing information including IT technology, digital television, and written directories. A report about IT services and the impact on the voluntary sector highlight interesting figures of the increasing use of modern technology (Evans & Saxton 2004). There has been a rise of 33% in those adults who have access to the internet and are now regular users, from 50% in 1999 to 83% in 2003. Forty five percent of regular users access the internet nearly every day. Digital TV has also experienced a rapid uptake with 44% of households accessing it within 5 years of introduction. This figure is predicted to rise to 70% by 2010. In five years time it is predicted that 90% of the UK population will have access to interactive services and activities in some way within their homes. Much of this will be due to the purchase of already established technologies such as televisions and mobile phones which will have interactive features built into them as the norm. The Department of Health launched four pilot projects in 2001 to explore the feasibility and effectiveness of health information and advice services supplied to the public via digital interactive television (Nicholas et al 2003). Evaluation of the pilot indicated that although numbers of users of the service were patchy between the four pilot projects, there were indications that the services have the potential to attract a large audience. This will be particularly significant when terrestrial television services are no longer available. An associated project which explored the use of digitally available health video's found that those who used the service tended to be avid seekers of

information, and they saw the service as a first stage to seeking information to be followed up with a health professional at a later date (Williams et al 2003).

The policy 'Better Information' aims to make full use of developing technologies in providing information to the public, and offering a variety of mechanisms by which they can access this information. However there is little discussion of the issues of equity with relation to new technologies. Whilst Evans and Sexton's report indicates that a large proportion of the public will have access to technological services within their home (Evans & Saxton 2004), there is likely to be a small minority who will be either unable to afford, or desire these services. It may also be likely that those unable to afford, or unwilling to use these new services may also be the most in need of health information and services.

The last section of the policy outlines how the strategy will be delivered. Crucial to this stage is the partnership between stakeholder organisations and the roles they will take. Clear objectives and expected end results are outlined, with reference to five key areas. One of these key areas is the empowering of people, to become more involved in their health by providing them with methods of access to health information personalised to them. It is acknowledged that a change in people's behaviour is required and that this will take time.

10.9 Conclusion

For many years health professionals have sought to deliver information to the public and their patients. Collaboration has existed between the NHS and other voluntary sector organisations in providing much of this information. However, there is a growing recognition that this information is provided in an ad-hoc manner with little regulation or overall strategy.

Political and social changes have focused upon a devolution of authority to more local agents, and the development of partnerships to provide more appropriate services to match the needs of local communities. Mounting evidence suggests that only making improvements in public health can bring about long-term reductions in health care costs. This has led to increased debate about the rights and responsibilities of individuals and how they use health services. These issues have had a strong impact upon the 'Better Information' policy, both in terms of the influences for the development of the policy, and also how the policy fits within the broader context of health services. The implicit rationale within the policy is that by providing personalised information, individuals will be empowered and will choose to take a more active responsibility for their health and health care choices. Alongside this, a more equal sharing of power in the relationship between user and provider will enhance this process.

The policy is still relatively new and therefore there is little evidence as to the efficacy of the policy in meeting its principles and aims. Some actions within the policy are likely to be quickly implemented, particularly those involving partnerships between the Department of Health and the private sector. Other aspects, such as the changes required in the training of health professionals, and their acceptance and ability to meet the targets, may take longer. The policy states the strategy has to be delivered by 2008. Ongoing monitoring and evaluation of the actions are written into the policy and only time will tell if they will be achieved.

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CHAPTER 11: SERVICE DEVELOPMENT PROJECT

11.1 Introduction

This service development project served as a small study as development work for the main project. The SDP considered issues around provision and accessibility of information services for individuals who have been affected by cancer. The results from this SDP were incorporated into the research proposal. The SDP assignment comprised of a Powerpoint presentation of five main slides and 1000 words which formed the basis of an oral presentation.

Accessing Health Information

Nicola Beech

Service Development Project

28th March 2006

11.2 How do people wish to access health information?

How do people wish to access health information?

➤ Policy: advocates partnership between health professionals and patient. Equitable access to information lays foundation for this partnership (DoH 2004).

➤ What are the potential/ actual barriers people experience with relation to accessing health information?

Slide 1

The Labour Government have focused on modernising the National Health Service (NHS) to become responsive to the changing health needs of the population during the 21st century. The principles for modernisation include:

- decentralisation of power from centrally held to local level for public services.
- more autonomy and power to the public to involve them in choices and decisions about their own health,
- partnership between service providers and recipients of services.

Information provision is seen as essential to foster and develop this 'partnership'. The implicit argument within many policies is that by providing individuals with information and choice, they will take a more active responsibility for their own health and lifestyle behaviours (DH 2000a; DH 2000b; DH 2001a; Dh 2001b; DH 2003; DH 2004a; DH 2004b; DH 2004c).

11.3 Background

Background

- Acheson Report (1998) All policies likely to have impact on health should be evaluated in terms of impact on health inequalities.
- Implicit argument within policy is that by providing individualised information, the public will then take a more active responsibility for their own health and lifestyle behaviours (DoH 2004).
- Improving Services, Improving Lives: deepen understanding why some groups benefit less from services (SEU 2005).
- "Better information alone will not produce more equity" (Braveman and Tarimo 2002).
- Higher quality and more tailored information could address "inverse information law". (Dixon et al 2003).

Slide 2

Policies and background literature which have influenced this service development project:

1. The Acheson report (1998) was an independent inquiry which summarised the inequalities of health of the population; and prioritised areas for policy development to address these inequalities. Health inequity refers to an avoidable disparity in health or its key determinants that are observed between groups of people with different levels of underlying social privilege. Social privilege varies by economic status, age, gender, ethnic group, geographical placement, education etc.
2. The policy 'Better information, better choices, better health' focuses on providing information to individuals, thereby enabling them to make certain choices about their health and lifestyle (DH 2004a).
3. The Social Exclusion Unit (2005) state the overall objective is to make public services more effective for disadvantaged people, in order to improve their life

chances. People can only make use of services if they know about them and 'think' they are for them. Accurate, accessible and appropriate information helps give people the knowledge, understanding and confidence that they need to engage with services.

4. Braveman and Tarimo (2002) state that equity implies consideration of need rather than social privilege in resource allocation.

5. Dixon et al (2003) comment on the inverse information law; the idea that those who are 'less well off' (i.e. disadvantaged) and therefore have greater need, are less well served by the service (i.e. information service).

An example of this inverse information law could be that the middle classes/ more articulate/ higher educated are more able to use their 'voice'. They are more likely to know where and how to access information, and may be more confident and persistent in accessing this information. Those less literate and articulate are less likely to be able to interpret/ understand information, or indeed know where to access it. Therefore, this service development project aims to consider the following question: What are the potential and/ or actual barriers people experience with relation to accessing health information?

11.4 Content, Context and Process Model

Content, Context and Process Model

Slide 3

This model was chosen because it considers the 'whole picture'. As this service development project relates to a national strategy and its implementation, some change models are too focused on individuals or teams. The policy is a national one, focusing on the practice of a wide range of professionals, both within the NHS and also voluntary sector.

11.4.1 Context

Context is defined as the 'why' and 'when' of change.

External factors include:

- economic/ business (increased patient control will result in decrease costs to NHS)

- political (decentralisation, ethos of user focused care and services)
- social (individual accountability for own health)

Internal factors include:

- resources (policy states that information not an add on, therefore implies should come from existing funding)
- capabilities (increased partnership between providers and users)
- culture (increased autonomy and power of individuals)
- politics (attempt to decrease demand for services, by educating individuals and providing power to them)

11.4.2 Content

Content is defined as the `what` of change and is concerned with the areas of transformation:

- assessment and choice of products (NHS, voluntary, independent)
- objectives and assumptions (enhancing understanding of users perceptions)
- targets and evaluation (identify which areas to develop and how)

11.4.3 Process

Process is defined as the `how` of change and refers to actions and interactions of stakeholders:

- change managers (variety key stakeholders, including users of services)
- models of change (have to consider applicability to national and local level)
- formulation/ implementation (various measures to be implemented)
- pattern through time

11.5 The Process

The Process

Method: Focus group Email consultation Face to face contact Appraisal of policy and protocols	Sample: Members of user groups Health professionals involved in setting up/ running services People accessing information services
Critique: Small sample Require repeated focus groups Self selected sample	Ethical issues: Third party introduction. All data confidential (focus group had own clause)

Slide 4

11.5.1 Method

Various data collection methods were used including a focus group; direct one-to-one email; interviews.

Appraisal of key policies and a selection of information service protocols.

11.5.2 Sample

I tried to ensure a wide range of people with relevant experience and ideas were included in the sample. Health professionals and experts who had been involved in developing and setting up information services were approached. I also relied on word of mouth recommendations.

Members of a regional cancer user support group.

Various health professionals and experts working in information service provision.

11.5.3 Critique

There were several limitations to this development project which aimed to develop ideas for the research project. The sample was quite limited and small numbers. Many were self selected by the researcher and participants. It was not possible to consider those who do not access services. The method of data collection was limited and requires further development.

11.5.4 Ethical issues

The use of a third party introduction to the user group ensured only those who initially agreed were approached.

All names and personal contact details were kept confidential.

Due to limitations of time and scale of project, it was not possible to return data to participants for validation.

11.6 Results and Future Progression

Results and Future Progression

Barriers relate to:

- location of services
- awareness of services
- nature of service provision
- nature and style of information provided
- lack of tailored personalised information

Slide 5

11.6.1 Location of services

Services are increasingly available in a variety of settings and formats:

primary and secondary health settings.

Community – libraries, help centres etc.

Technology e.g. internet, digital tv etc.

However, participants state want services in places convenient for them, predominantly community based.

11.6.2 Awareness of services

Key areas relates to advertising of services: more work required on community advertising for example local radio/ newspapers/ community groups etc.

People want services in places they use, one gentleman suggested working men's clubs and the pub!

They want these services in their locality and also want them advertised.

Many were unaware of what services were available locally to them.

Also unclear about whether the service was there for them.

Many wanted services based away from hospital settings.

11.6.3 Nature of service provision

People want informal settings, comfortable surroundings (seating etc).

Most importantly they want someone they can discuss the information with, ideally a health professional or a skilled information worker. Many said that being given a leaflet was not enough, they wanted to talk through the leaflet with people to ensure they understood what they had read.

11.6.4 Nature and style information provided

Too much information is paper based. Alongside this, much of Government policy focuses on increased technology for imparting information eg. Digital tv, internet etc.

People repeated that they wanted to talk with someone. They felt it was likely that many of those who don't access services may also not have access to modern technology.

One gentleman stated that much information available electronically has been simply 'copied' from written leaflets.

This does not address the literacy and education issue.

11.6.5 Lack tailored personalised information

Need for skilled professionals to talk with users.

They want to ensure the information is relevant to them.

Some services not perceived as personal and relevant to individuals.

11.6.6 Areas for further exploration:

Advertising of services: review and consideration of current mechanisms used, and how to enhance ability to reach disadvantaged i.e. low literacy, non English speaking, those without access to internet etc.

Consideration of various forms information presentation (written, audio, tv etc.)

Different levels information provided and how to ensure appropriate.

Ranges of different user needs.

11.7 Conclusion

People report they want information to be tailored to their specific needs and they want to access this information face to face. Issues of equity of information provision are improving in that more services are available, and in a wider range of areas and provision styles. However, the sample in this study still believed inequity in access existed, particularly for those who were disadvantaged in some way. External forces from Government and local health authorities are 'pushing' for change but these 'changes' might not reflect the needs of the population, nor provide services in the manner in which people wish them to be provided.

11.8 References

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