

**An exploration of patients' perceived control,
self efficacy and involvement in self care
during chemotherapy for colorectal cancer**

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Abstract

This thesis describes a three year study which explored perceptions and experiences of being involved in self care and perceptions of control and self-efficacy over time amongst patients receiving a six month course of chemotherapy treatment for colorectal cancer. The study was underpinned by Leventhal's Self Regulation Model and aimed to explore how patients undergoing chemotherapy for colorectal cancer perceived the meaning of self care, what they did as part of their self care in managing the effects of their treatment and whether this changed between the beginning and end of their six month course of chemotherapy. The study also set out to explore the relationship between patients' perceptions of control and self efficacy and their involvement in self care.

The study adopted a patient focussed, mixed method, longitudinal approach for complementarity and expansion purposes in which the qualitative findings formed the focus of the investigation, supplemented by the quantitative findings. This was important to provide a greater breadth and range to the study and to obtain a realistic understanding of patients' perceptions and experiences of being involved in self care during their six month course of chemotherapy treatment and the influence of their perceptions of control and self efficacy on their involvement in self care. Thirty one patients participated in the study and data were collected using qualitative semi structured interviews (with a subsample of patients who participated in the study) and quantitative questionnaires (Illness Perception Questionnaire-revised and the Strategies Used by People to Promote Health) and prospective self care diaries with the full study sample. Data were collected at several time points over the course of patients' chemotherapy treatment (beginning, middle and end of treatment) and were analysed and integrated in accordance with Tashakkori and Teddlie (1998)'s guidance for integrating qualitative and quantitative findings in a mixed methods study.

The study findings revealed that the use of a mixed method, longitudinal study design was a valuable approach for understanding patients' involvement in self care during chemotherapy for colorectal cancer and the influence of factors, such as their perceptions of control, on their subsequent involvement in their self care. In particular, the principal findings suggested that self care held a range of meanings to the patients in this study. Principally, patients' self care consisted of two components; physical self care, carried out to manage the physical impact of undergoing treatment, and emotional self care, carried out to manage their emotional response to being diagnosed with, and undergoing treatment for, cancer. The findings suggested that there was no association between patients' perceptions of control and the degree of self care that they carried out identified in the quantitative analysis. However, in the qualitative analysis, it was revealed that patients' perceptions of control were likely to influence their attitudes towards their active involvement in self care and the importance with which they viewed this role. In particular, patients who considered themselves to have a high degree of control during their treatment were more likely to believe that they could limit the impact of the treatment through their own actions, that being actively involved in their self care was important and were interested in taking on this role, and that they would use a greater range of self care strategies in helping to manage the impact of their treatment. Conversely patients who considered themselves to have a lower degree of control during their treatment were less likely to believe that they could limit the impact of the treatment through their own actions, that their active involvement in self care was important and were less likely to expect to take on an active role, preferring to leave the management of treatment-related effects to health professionals, whom they regarded as being the "experts".

The findings from this study have implications for nursing practice because they reinforce the importance of the listening to the patient's experience and how this approach can contribute to a fuller and more accurate understanding of how patients become involved in their self care and the factors that influence this. This is important so that nurses can

provide holistic care, tailored to meet their patients' self care needs and preferences, and to encourage partnership working between patients, nurses, allied health professionals and other agencies in promoting involvement in self care. The findings also have implications for theories relating to self care in emphasising the importance of patient centred models of care and for Leventhal's Self Regulation Model in adding further support for the components of the model yet also offering a greater understanding of how the model fits with patients' emotional responses to the effects of illness and its' treatments. Finally, the study findings have implications for future research, calling for further research to focus on the meaning of constructs such as self care and control from the patients' perspective and to further explore the use of the mixed methodology in researching and understanding patients' involvement in self care and the factors that influence this.

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Declaration

I declare that this thesis embodies the results of my own research and that I am the full author of this thesis.

Signature _____

Date _____

Chapter 1 Introduction

1.1 Research Problem

The ideas for this thesis were generated from the researcher's interest in understanding the rationales for why patients with cancer do and do not become involved in their self care whilst undergoing chemotherapy treatment for cancer. In particular, the researcher became interested in this because of her previous discussions with clinical staff and colleagues who expressed concern for patients who were often re-admitted to hospital with a deterioration in their health status because of poorly managed treatment-related side effects. When examined, the literature also confirmed that there was an increasing need for patients to take a greater role in managing treatment-related side effects because of the shift in care from acute to community and outpatient based care, where ultimately patients and health professionals had limited time together, and hence, effective symptom management was severely hampered (McCaughan and Thompson, 2000; Hubbard et al, 2007).

Interest in self care has also recently been ignited in the UK within current health policy since self care has assumed an important role in the new policy reforms which favour a proactive model of care focussing on the management of long term conditions, predominantly within a community based setting, as opposed to a reactive model of care based within acute clinical settings (Department of Health, 2000, 2001, 2005a, 2005b, 2006a; Scottish Executive, 2003, 2005a, 2005b). In relation to patients with cancer, the past decade has seen the introduction of new and complex treatment options for patients with colorectal cancer which frequently involve the use of multiple combinations of chemotherapeutic drugs or the use of oral chemotherapies. There is also a growing interest in the potential for patient administration of home based chemotherapy. These options create implications for patients in terms of their self care since they increase the likelihood of patients experiencing potentially toxic treatment-related side effects outwith the direct attention of health professionals and which require prompt and effective management in

order to prevent them from adversely affecting the course of the patients' treatment and from affecting their quality of life (Larson et al, 1998; Dodd and Miaskowski, 2003).

1.2 Purpose of the Research

In this study, the researcher set out to explore how patients undergoing chemotherapy for colorectal cancer perceived the meaning of self care, whether self care was important to them, what they did as part of their self care in managing the effects of their treatment between the beginning and end of their six month course of chemotherapy, and whether their individual perceptions of control and self efficacy changed over time and how these perceptions influenced whether they carried out a greater or lesser degree of self care. The study was conducted in the hope of making a contribution to current practice by providing a realistic account of patients' individual perceptions towards, and experiences of, being involved in self care during chemotherapy treatment for cancer. It was intended that this could help health professionals to better understand patients' responses to self care and the influence of their perceptions of control and self efficacy on their self care decision making so that support and guidance for helping patients to become involved in self care could be tailored and individualised around such perceptions and experiences. Furthermore, the researcher wanted to further the body of existing knowledge by conceptualising self care from a patient's perspective since existing conceptual and theoretical frameworks fail to acknowledge the importance of this and the reality of patients' involvement in self care. It was hoped that the study would highlight the value in using a qualitative, patient focussed approach, in comparison with a quantitative approach, in understanding the reality of patients' perceptions and experiences of their involvement in self care during chemotherapy treatment for colorectal cancer.

The goal of this study was, therefore, to use a mixed method, longitudinal approach to explore perceptions and experiences of being involved in self care and perceptions of

control and self-efficacy amongst patients receiving chemotherapy treatment for colorectal cancer.

1.3 Rationale for Methodology

Given that the majority of existing research on self care in patients with cancer has been conducted from a quantitative perspective (Dodd, 1982, 1983; 1987; 1988; Nail et al, 1991; Foltz et al, 1996; Hagopian, 1996; Richardson and Ream, 1997; Benor et al, 1998; Braden et al, 1998; McDaniel and Rhodes, 1998; Craddock et al, 1999; Borthwick et al, 2001; Oliver et al, 2001; Wydra, 2001; Seegers et al, 2003; Given et al, 2004; Miaskowski et al, 2004; Williams and Schreier, 2004; Wong et al, 2006), the researcher was keen to include this component within the current study, alongside a qualitative approach, which has previously been found to be valuable for understanding the meanings that individuals ascribe to self care (Dill et al, 1995; Plach et al, 2005) and their rationales for involvement, or non involvement, in self care (Sims, 1999; Riegel and Carlson, 2002; Horowitz et al, 2004). This approach, however, has not been used to explore such perceptions and experiences of self care in patients with cancer.

Furthermore, there is no existing research which has investigated how the perceptions and experiences of being involved in self care, and perceptions of control and self efficacy change over time in patients undergoing a six month course of chemotherapy treatment. Patients' perceptions of their illness and their self care responses in managing the impact of illness and treatment are likely to change over time (Paterson and Thorne, 2000). Therefore, patients' involvement in self care decision making cannot be seen as a static, one time event, but an ongoing process which is likely to change over time (Paterson et al, 2001). Subsequently, the researcher considered that it would be valuable to combine the use of qualitative and quantitative approaches in a longitudinal study to determine the ways in which patients' involvement in self care and their perceptions of control and self efficacy change over the duration of their treatment.

To understand the reality of patients' perceptions towards, and experiences of, being involved in self care during their six month course of chemotherapy treatment, the researcher considered that a patient focussed approach which combined different perspectives would be particularly useful for expanding the breadth and range of the investigation and important for developing a realistic understanding of patients' involvement in self care and their perceptions of control and self efficacy. The researcher also wanted to quantify and determine associations between changes in the degree of self care, and the types of self care activities carried out by patients and changes in their perceptions of control and self efficacy between the beginning and end of their treatment and to compare and contextualise these findings with the qualitative data to explore the lived experience of self care. In particular, the researcher considered that the qualitative findings would complement the quantitative findings in terms of offering an understanding of how patients made sense of their involvement in self care, and changes in their involvement in self care, and the importance of their perceptions of control and self efficacy and how these influenced their self care behaviours.

This thesis argues that a mixed method design was valuable and important for comparing the findings from a qualitative and quantitative approach and for providing a detailed and realistic understanding of patients' perceptions and experiences of being involved in self care during their six month course of chemotherapy treatment and the influence of their perceptions of control and self efficacy on their involvement in self care.

1.4 Structure of the Thesis

The following chapters of this thesis begin with a review of the literature on self care, control and self efficacy that was pertinent to the development and findings of the current study (Chapters 2, 3 and 4). The literature in these chapters was identified from various sources, including database searches, PhD theses and conference proceedings. Reference lists of key research papers, cited author searches, and hand searching of relevant journals

was also conducted. Table 1.1 identifies the databases that were searched and the key words that were used in these, along with the names included in the cited author search and the names of the relevant journals that were manually searched.

| | |
|---------------------------------|--|
| Databases | Cinahl Cochrane Library Medline PsychInfo |
| Keywords | Cancer Chemotherapy Colorectal cancer Expert patient Illness representations/perceptions Involvement Perceived control/locus of control/control/personal control Self care Self efficacy Self management Symptom management Symptoms/side effects |
| Data range | No limits on date ranges were applied in any of the searches |
| Cited author search | Bandura, A Barlow, J Bury, M Cassidy, J Coulter, A Dodd, M Lev, E Leventhal, H Lorig, K Moss Morris, R Ream, E Richardson, A Weinman, J |
| Handsearch of relevant journals | Cancer Nursing European Journal of Cancer Care European Journal of Oncology Nursing Health and Social Care in the Community Health Expectations Oncology Nursing Forum Patient Education and Counselling Supportive Care in Cancer |

Table 1.1: Details of databases, keywords, date ranges, names of cited author searches, hand searches of relevant journals undertaken as part of the literature review strategy in the thesis

Chapter 2 considers the current practice in the management of colorectal cancer with chemotherapy treatment and its historical development to date in terms of patterns of its use. It finishes by discussing the growing need for self care amongst patients undergoing chemotherapy for colorectal cancer in light of the changes seen in the use of different types of chemotherapy and organisational changes in service delivery. In Chapter 3, the

conceptual and theoretical underpinnings of self care are considered highlighting the difficulties in defining self care and the lack of the patient's perspective within these conceptualisations and many of the theoretical models relevant to self care. This chapter explains the use of Leventhal's Self Regulation Model as the theoretical basis for this study. The drivers behind the growing importance of patients' involvement in self care and studies on the impact of self care on outcomes in patients with cancer are then considered. This discussion reveals that despite policy support for involving people in their self care, the evidence base to support the policy recommendations is weak and far from robust. The chapter also considers some of the existing research which has investigated the perceptions of patients and health professionals towards self care and in doing so, highlights the lack of research which has focussed on the perceptions of patients with cancer. The chapter finishes with a critical consideration of existing research which has focussed on the outcomes of informational self care interventions and structured self management programmes in patients with cancer. The discussions in Chapter 4 highlight the complexity surrounding the conceptualisation of perceived control and its relationship to self efficacy, and considers some of the existing research on perceived control and self efficacy in patients with cancer, before finishing with a consideration of some of the studies that have investigated the association between perceived control, self efficacy and self care. This discussion highlights that the predominant use of quantitative, cross sectional methodologies have done little to identify how patients' perceptions of control and self efficacy change over time and the rationales behind patients' perceptions of control and self efficacy.

The discussion in Chapter 5 follows the arguments made in these chapters and explores the need to understand patients' perceptions and experiences of self care using a patient focussed, individualised approach and highlights the rationale for adopting a mixed method, longitudinal approach in the current study. Chapter 6 describes in detail the aims, study design, sample recruited to the study, and the rationales for the choice of the particular

methods that were employed in exploring and determining changes over time in patients' perceptions and experiences of self care, control and self efficacy. The chapter also considers how this data was analysed. In Chapter 7, the conduct and the findings from the pilot study are presented and the modifications that were made in preparation for the main study.

In Chapters 8-11 the study findings are described. In particular, Chapter 8 presents the details relating to the sample that was recruited to the study (including accrual, demography, attrition and the challenges encountered by the researcher during recruitment), the quality of the data and its management, and the reliability of the quantitative instruments used in the study. Chapter 9 presents the findings from the qualitative analysis of the semi-structured interviews and the recurring themes which originated from these in relation to patients' perceptions and experiences of their involvement in self care. In Chapter 10, the quantitative analysis of the questionnaires and self care diaries are described. In particular, the chapter describes the changes in, and associations between, patients' perceptions of their degree of involvement in self care, and their perceptions of control and self efficacy over their six month course of chemotherapy treatment. The final results chapter, Chapter 11, presents the triangulated findings from the qualitative analysis of the semi structured interviews and the quantitative analysis of the questionnaires and self care diaries. This is followed by Chapter 12, in which the challenges encountered with the methodology adopted in the study and its' strengths and weaknesses are considered and the study findings discussed in relation to the wider literature and existing research. The implications of the study findings for nursing practice, theories relevant to self care and future research are also considered in this chapter.

Chapter 2 Management of Colorectal Cancer

2.1 Introduction

Colorectal cancer is the general name for the group of cancers which involve the colon and the rectum. This chapter presents a brief overview of the clinical presentation of colorectal cancer and its incidence in the UK, and considers its management using systemic chemotherapy. Chemotherapy is used in the management of a large number of patients with colorectal cancer. The relationship between the patient's stage of cancer and the nature, and types, of chemotherapy, which may be given as part of their treatment is discussed in this chapter. The chapter also considers the changes that have affected the types, as well as the delivery, of chemotherapy that is offered to patients with colorectal cancer, and the implications that these have for patients in relation to their self care.

2.2 Incidence of Colorectal Cancer

Colorectal cancer is amongst the most common cancers in Scotland, accounting for 14.7% and 11.3% of all cancers affecting men and women respectively (ISD, 2006). It is the third most common cancer, after lung and breast cancer in the UK, (Cancer Research UK, 2007), with over 35,000 new cases being diagnosed each year, and is the second most common cause of cancer death after lung cancer, with more than 16,000 deaths being reported in 2002 (Cancer Research UK, 2007). There have been significant improvements in five-year survival rates for patients with colorectal cancer in the last 30 years (Cancer Research UK, 2007) as a result of advances in surgery and treatment (National Institute for Health and Clinical Excellence (NICE), 2004). However, survival rates are worse in those patients who initially present with advanced stage cancer and who are, therefore, less amenable to treatment (NICE, 2004). The following section discusses the clinical presentation of colorectal cancer and identifies the difficulties associated with its early detection.

2.3 Clinical Presentation of Colorectal Cancer

Colorectal cancer usually develops over a period of many years. It is believed to arise through a process known as the ‘adeno-carcinoma sequence’ (Cummings, 2000), in which, cells within the colon mutate and grow into a polyp, commonly referred to as an adenoma (de Snoo, 2003). Adenomas are benign growths, meaning that they are non-cancerous, although, they can mutate and become cancerous over a period of years (de Snoo, 2003). O’Brien (1990) claimed that on average a polyp, or adenoma, takes five years to initially develop, and then a further five years to develop into a cancerous tumour. Many patients with early colorectal cancer are asymptomatic (Muma, 2000; NICE, 2004), whilst others experience vague and variable symptoms such as weight loss, abdominal pain, changes in bowel habits (alternating between constipation and diarrhoea) and rectal bleeding, which are also often associated with other conditions such as inflammatory bowel disease and haemorrhoids (Knowles, 2002; Booth et al, 2004; NICE, 2004). Colorectal cancer can, therefore, be difficult to detect early and hence, many patients are diagnosed from the outset with metastatic spread (Muma, 2000).

2.4 Aetiology of Colorectal Cancer

The majority of colorectal cancers tend to occur within the colon (two thirds), and then the rectum (one third) (NICE, 2004). Much research has been, and continues to be, devoted to the aetiology of colorectal cancer. Demographic factors such as age, culture and race, and socioeconomic status continue to be linked with the onset of colorectal cancer. In particular, older age (NICE, 2004; Libutti et al, 2005), living in Western, industrialised nations (Nicum et al, 2003), being African American (Kiefe, 2002) and being of a lower socioeconomic status (Auvinen and Karjalainen, 1997) has previously been associated with an increased susceptibility to developing colorectal cancer however, the evidence on the influence of such factors is often conflicting. Other lifestyle risk factors such as dietary intake, level of physical activity or sedentary occupation, alcohol intake, and smoking (see Table 2.1), are also the subject of many case control and prospective cohort studies

conducted in many different countries throughout the world. Many studies have reported an association of these factors with risk of colorectal cancer (Gerhardsson et al, 1988; Howe et al, 1992; Giovannucci et al, 1993; White et al, 1996; Slattery et al, 1997; Slattery et al, 1998; Sturmer et al, 2000; Giovannucci, 2001; Ji et al, 2002; Bingham et al, 2003; Diergaarde et al, 2003; Fung et al, 2003; Otani et al, 2003; Slattery et al, 2003), whilst others have reported no such association (Fuchs et al, 1999; Almendingen et al, 2000; Michels et al, 2000; Flood et al, 2002; Terry et al, 2003; Asano and McLeod, 2004).

Mutations in specific genes associated with colorectal cancer, for example the Adenomatous Polyposis Coli (APC) gene (Luchtenborg et al, 2004; Muzaffarova et al, 2005), and MLH1 and MSH2 genes (Wagner et al, 2003) and illnesses such as inflammatory bowel disease (Hardy et al, 2000; Rossman-Urbach et al, 2004; Maia et al, 2005) also increase an individuals' susceptibility to developing colorectal cancer. However, the strength of the relationships between many of these risk factors and risk of colorectal cancer, and indeed the mechanisms underlying these relationships, are still unclear and many studies suffer methodological limitations since they are predominantly case control and prospective cohort studies. Such limitations may include inadequate sample sizes, difficulties in controlling for confounding factors, difficulties in matching cases and controls (Grimes and Schulz, 2002) and, particularly in prospective cohort studies, selection bias, difficulties with the length of time required for the study and attrition rates (Grimes and Schultz, 2002). By way of summary, Table 2.1 details some of the lifestyle, genetic and illness related risk factors putatively associated with colorectal cancer risk, their potential mechanisms of action and studies which have investigated their associations.

| Risk factor (s) | | Potential mechanisms of action | Selected studies which have investigated the relationship with CRC |
|-------------------------------------|-------------------------------------|---|---|
| Lifestyle risk factors | | | |
| Dietary intake | Fruit, vegetables and dietary fibre | Reduced exposure of colonic mucosa to carcinogens due to the dilution, absorption, and shortened transit time that results from increased fibre (Asano and McLeod, 2004) By-products of fibre degradation may reduce the activity of tumour promoters (Asano and McLeod, 2004) | Slattery et al (1998); Fuchs et al (1999); Michels et al (2000); Flood et al (2002); Bingham et al (2003); Fung et al (2003); |
| | Red meat, fats and sugars | Fat from red meat may be less digestible in the small intestine, thus more may reach the large intestine (Giovannucci et al, 1994) Red meat may increase concentrations of faecal iron which could generate hydroxyl radicals and increase risk of CRC (Giovannucci et al, 1994) Increased calorie intake may increase insulin in the blood which may increase risk of CRC (Hu et al, 1999; Sandhu et al, 2001) | Slattery et al (1997); Slattery et al (1998); Fung et al (2003); Terry et al (2003) |
| | Alcohol | Alcohol or its constituent parts may trigger carcinogenesis (Salaspuro, 1996; Choi et al, 1999) Greater alcohol intake may affect immune suppression, delay of DNA repair or changes in bile acid composition (Longnecker et al, 1990) | Giovannucci et al (1993); Ji et al (2002); Otani et al (2003) |
| Physical Activity/Inactivity | | Low physical activity may prolong the transit time of the faecal matter in the colon and thereby increase exposure of the colonic mucosa (Gerhardsson et al, 1988) Protective effect against insulin and insulin growth factors (identified as increasing risk of CRC) and unsaturated fats and serum cholesterol (Quadriatero and Hoffman-Goetz, 2003) | Gerhardsson et al (1988); White et al (1996); Slattery et al (2003) |
| Smoking | | May increase risk of adenoma formation by the effects of carcinogens in tobacco on the expression of cancer genes, such as the APC, K-ras, and p53 genes (Giovannucci, 2001; Diergaarde et al, 2003) | Almendingen et al (2000); Sturmer et al (2000); Ji et al (2002); Diergaarde et al (2003); Otani et al (2003) |
| Genetic risk factors: | | | |
| APC gene | | Linked to the development of 'Familial Adenomatous Polyposis' (FAP) Mutations in both copies of the APC gene result in an increased risk of developing adenomatous polyps and the initiation of the adeno-carcinoma sequence, leading to the development of colorectal cancer (Glaser, 1998; Rudy and Zdon, 2000). | Luchtenborg et al (2004); Muzaffarova et al (2005) |
| MLH1 and MSH2 genes | | Linked to the development of 'Hereditary Non-Polyposis Colorectal Cancer' (HNPCC) Mutations in these genes do not directly lead to colorectal cancer but fail to correct random mutations in critical oncogenes and tumour suppressor genes, leading to the development of colorectal cancer (Marra and Boland, 1996) | Wagner et al (2003) |
| Illness-related risk factors | | | |
| Inflammatory bowel disease | | Relationship is still unclear Patients with inflammatory bowel disease have been found to have abnormalities in MLH1 and MSH2 genes, related to the development of HNPCC (Brentnall et al, 1995) | Rosman-Urbach et al (2004); Maia et al (2005) |

Table 2.1: Summary of lifestyle, genetic and illness related risk factors associated with colorectal cancer

2.5 Management of Colorectal Cancer

As is discussed further in section 2.5.1, the approach taken in the management of colorectal cancer depends upon the stage of the cancer and the intention of the treatment. Surgery to remove the tumour is performed where possible and offers the only chance of cure (Scottish Intercollegiate Guidelines Network (SIGN), 2003) with cited 5-10 year survival rates of between 20 and 63% (Nicum et al, 2003). Radiotherapy is considered to be more appropriate for managing tumours of the rectum, rather than tumours of the colon and has often been used in these cases either neoadjuvantly, to reduce the size of the tumour prior to surgery (Glimelius, 2002), adjuvantly, to help prevent local recurrence (Glimelius, 2002), and palliatively, to relieve symptoms such as pain and bleeding (SIGN, 2003). Systemic treatment in the form of chemotherapy is offered to many patients with colorectal cancer, although as the following discussion highlights, its exact form varies depending upon the extent of the patients' cancer. Given that the current study was conducted in patients undergoing chemotherapy for colorectal cancer, the following discussion focuses on the role of chemotherapy treatment in the management of colorectal cancer.

2.5.1 Stage of Disease and Chemotherapy Treatment

The decision to offer chemotherapy treatment to patients with colorectal cancer and, the choice of treatment regimen, is determined by the pathological stage of the tumour. Pathological staging occurs following the patient's initial surgery and is also important for determining the patient's potential outcome in terms of survival (Table 2.2). Dukes' A colorectal cancer means that the tumour has superficially invaded the inner-most layer of the bowel wall (the mucosa), in Dukes' B colorectal cancer the tumour has penetrated into or through the muscular layer of the bowel wall but not into the regional lymph nodes, and in Dukes' C colorectal cancer the cancer has spread to regional lymph nodes (Knowles, 2002). Patients who initially present with Dukes' C colorectal cancer are more likely to develop metastatic disease than patients with Dukes' A or B colorectal cancer (Lev and Lee, 1995).

| Stage | 5-year survival |
|----------|-----------------|
| Dukes' A | 83% |
| Dukes' B | 64% |
| Dukes' C | 38% |

Table 2.2: Five year survival in colorectal cancer (Campbell et al, 2001)

It is important to note that the clinical management of cancer of the colon and rectum can differ. To prevent confusion, the following discussion refers to cancers of the colon in relation to treatment for both early and metastatic cancer. A brief mention of the management of cancer of the rectum is considered thereafter in section 2.5.4.

2.5.2 Adjuvant Chemotherapy for Colon Cancer

Following the patient's initial surgery, adjuvant treatment is given with the aim of eliminating micrometastases in order to reduce the risk of the tumour recurring (Nicum et al, 2003). It is firmly believed that there is no role for chemotherapy treatment in patients with Dukes' A colorectal cancer as these patients have a low risk of developing recurrent disease whilst, adjuvant chemotherapy for patients with Dukes' C colorectal cancer is widely used (Maguire, 2002) since these patients have a high risk of developing recurrent disease (Benson et al, 2004). Several clinical trials, including the the North Central Cancer Treatment Group (NCCTG) trial (Laurie et al, 1989), the US Intergroup trial (Moertal et al, 1990), the International Multicentre Pooled Analysis of Colon Cancer Trials (IMPACT) (IMPACT, 1995), and the Quick And Simple and Reliable (QUASAR) study (QUASAR Collaborative Group, 2000) and the X-ACT study (Cassidy et al, 2004), which have included patients with Dukes' C colorectal cancer, have consistently shown reductions in rates of recurrence and improvements in disease free survival using 5-fluorouracil based treatments. Consequently, the standard regimen for patients with Dukes' C colorectal cancer has become 5-fluorouracil in combination with leucovorin for 6 months, starting 6-12 weeks following surgery (usually given as the 'Mayo Clinic Regimen', which is discussed further in 6.4).

The benefits of adjuvant chemotherapy in patients with Dukes' B colorectal cancer are however, less clear and consequently, its role has been the subject of much debate. Recent data from the Netherlands Adjuvant Colorectal Cancer Project (NACCP) (Taal et al, 2001) and, most recently, the QUASAR study (Gray et al, 2004) and the MOSAIC trial (Andre et al, 2004), have reported improved disease free survival rates using 5-fluorouracil based treatments in patients with Dukes' B colorectal cancer. Despite this, there is still some question over the quality of the direct evidence available from randomised controlled trials because of the relatively good prognosis for patients with Dukes' B colorectal cancer and inadequacies in the sample sizes within these trials as well as the limited numbers of high risk patients recruited within these trials (Benson et al, 2004). As a result, there is little evidence to suggest a statistically significant survival benefit using adjuvant chemotherapy in patients with Dukes' B colorectal cancer. The most recent guidance available, produced by the American Society of Clinical Oncology (ASCO), have at the current time, concluded that the routine use of adjuvant chemotherapy for medically fit patients with Dukes' B (stage II) colorectal cancer is not recommended (Benson et al, 2004). Furthermore, although the most recent guidance in the UK (SIGN, 2003; NICE, 2004) supports this position, there has been further evidence produced since then which provides support for the use of adjuvant chemotherapy in patients with Dukes' B colorectal cancer (Andre et al, 2004; Gray et al, 2004; Wang et al, 2004; Wolmark et al, 2005). Subsequently, a commonly held principle amongst oncologists is that high risk patients should be considered for treatment with adjuvant chemotherapy (Professor Cassidy, personal communication, January 2007).

2.5.3 Chemotherapy for Metastatic Colon Cancer

Colorectal cancer most commonly metastasises to the liver (Nicum et al, 2003). Metastatic disease is usually incurable, therefore, chemotherapy in this group of patients is directed towards prolonging survival, symptom relief, and maintaining or improving quality of life (Holmes, 1997). Evidence from two systematic reviews, collectively comprising a total of

19 randomised trials and 1979 patients with metastatic colorectal cancer, supports the use of chemotherapy for metastatic colorectal cancer as it can prolong survival (Colorectal Cancer Collaborative Group, 2000; Jonker et al, 2000) and maintain patients' quality of life (Maughan et al, 2002). Hence, it should be considered in all cases. Without treatment, the approximate survival period following diagnosis is 6-9 months (National Institute for Health and Clinical Excellence (NICE), 2005). In recent years, the standard treatment for patients with metastatic colorectal cancer has been fluorouracil based treatments in the form of the De Gramont regimen (SIGN, 2003), and the more recently approved FOLFOX regimen (Hickish et al, 2004; Waterston and Cassidy, 2005; Cassidy et al, 2007), which combines oxaliplatin in addition to 5-FU and leucovorin. There have also been encouraging results from clinical trials of other new agents such as, Capecitabine (Van Cutsem et al, 2001; Hoff et al, 2001), Capecitabine in combination with Oxaliplatin (Cassidy et al, 2004; Bennouna et al, 2007; Cassidy et al, 2007), and Irinotecan (Cunningham et al, 1998; Rougier et al, 1998; Saltz et al, 2000), in patients with metastatic colorectal cancer, increasing the number of treatment options available to patients.

2.5.4 Management of Rectal Cancer

Surgery is the primary treatment modality in the management of rectal cancer, however, because some rectal tumours have a high risk of recurring, radiotherapy or a combination of chemotherapy and radiotherapy (chemoradiation) is offered to some patients pre-operatively (Glynne Jones and Mawdsley, 2005). This is referred to as neoadjuvant treatment and it is frequently used to increase the potential for curatively removing the tumour, preserving anal sphincter function, and to help reduce the risk of micrometastatic disease hence, influencing both survival and quality of life (Glynne Jones and Mawdsley, 2005). The efficacy of pre-operative radiotherapy has been explored in a recent meta-analysis (Camma et al, 2000; Colorectal Cancer Collaborative Group, 2001), which show a significant reduction in local recurrence, yet the latter, failed to demonstrate a significant survival advantage. Some phase II clinical trials have also shown that the use of

chemoradiation can increase the patient's chance of 5-year survival to as much as 90% (Ruo et al, 2002). Following surgery, the decision to offer chemotherapy is based on the pathological stage of the tumour and evidence of clear resection margins surrounding the tumour.

The mainstay of standard chemotherapy treatment for adjuvant and metastatic colorectal cancer in the past few decades has been 5-fluorouracil (5-FU) based regimes (Waterston and Cassidy, 2005). Advances in chemotherapy have also been reflected in the pattern of care in patients with colorectal cancer. Some of these changes include the use of different combinations of chemotherapeutic drugs (for example, Erlichman et al, 1988; LaBianca et al, 1991; Haller et al, 2003) and the development of new drugs (for example, Van Cutsem et al, 2001; Cassidy et al, 2004), as well as changes to the structure of cancer services (Fitzsimmons and Middleton, 2006) and the delivery of chemotherapy (for example, Lokich et al, 1989; Johansson et al, 2005). The following discussion presents a historical perspective of the use of chemotherapy in patients with colorectal cancer, beginning with a brief discussion of 5-FU and focussing on the use of the 'Mayo Clinic Regimen', which at the time of the start of this study, was the standard adjuvant treatment offered to patients with colorectal cancer.

2.6 Historical Perspective

2.6.1 5-Fluorouracil

5-fluorouracil (5-FU) comes from a group of anti-tumour agents known as the 5-Fluoropyrimidines (Nicum et al, 2003) and is an analogue of the naturally occurring pyrimidine, Uracil (Maguire, 2002). In relation to the mechanisms of action, 5-FU becomes cytotoxic following intracellular conversion to active metabolites and inhibits the enzyme thymidylate synthase and thus, the synthesis of thymidine, DNA and RNA (Nicum et al, 2003), all of which are involved in cell reproduction. Hence, inhibition of these factors leads to a decrease in cell production. As highlighted in section 2.6.2, the poor survival

outcomes seen using single agent 5-FU (for example, Petrelli et al, 1987; Nobile et al, 1988; Labianca et al, 1991; Advanced Colorectal Cancer Meta-Analysis Project, 1992), led many researchers to compare the efficacy and therapeutic effects of administering 5-FU in combination with other drugs and agents for example, leucovorin, with single agent 5-FU. Others, discussed in section 2.6.3, have focussed on the schedule of delivery of 5-FU based regimens, in particular, comparing the efficacy of bolus versus continuous infusion (for example, Lokich et al, 1989; Blijham et al, 1996).

2.6.2 Biomodulation of 5-FU

During the late 1980's and early 1990's, several clinical trials were conducted to investigate the use of 5-FU in combination with folinic acid (Petrelli et al, 1987; Erlichman et al, 1988; Nobile et al, 1988; Petrelli et al, 1989; Poon et al, 1989; Valone et al, 1989; Doroshaw et al, 1990; Labianca et al, 1991). These studies in over 1300 patients with colorectal cancer demonstrated an improvement in response rates when compared with single agent 5-FU, but only one study demonstrated a significant improvement in overall survival (Erlichman et al, 1988). A meta-analysis of 9 clinical trials, including 1318 patients, which compared single agent 5-FU with 5-FU and folinic acid, carried out by the Advanced Colorectal Cancer Meta-Analysis Project (1992), demonstrated improved response rates, but again, little difference in median survival between the groups. More recent studies, comparing the combination of 5-FU and levamisole, with and without the addition of leucovorin, have demonstrated significant improvements in disease free survival in favour of the leucovorin group (Taal et al, 2001; Porschen et al, 2001; Staib et al, 2001; Haller et al, 2003). Two of these trials concluded that the addition of levamisole offered no additive benefit in adjuvant treatment, but the combination of 5-FU and leucovorin, has been noted as having a relatively safe and manageable side effect profile (Wolmark et al, 1988; Haller et al, 2003).

2.6.3 Schedule of Delivery

Studies beginning in the late 1980's compared the efficacy and safety of infusional (where the drug is given steadily over a specific period of time, for example several hours) versus bolus (where all of the drug is given relatively quickly in one injection) schedules of 5-FU (Lokich et al, 1989; Blijham et al, 1996; Hansen et al, 1996), and have generally supported infusional schedules to be superior to bolus schedules (SIGN, 2003). In 1998, the Meta-analysis Group in Cancer (1998) analysed all clinical trials of 5-FU in patients with advanced CRC over a 10-year period and confirmed that there was a significant improvement in tumour response rates when using an infusional schedule. Furthermore, the use of infusional schedules have been found to reduce the frequency of myelosuppression, and the severity of mucositis and diarrhoea, compared with that of a bolus schedule (Lokich et al, 1989). However, a significant rise in the frequency of plantar-palmer syndrome, where the palms of the hands and soles of the feet can become red, inflamed and blistered, has also been noted with the use of infusional schedules (Lokich et al, 1989).

2.6.4 The Mayo Clinic Regimen

The 'Mayo Clinic regimen' has, until very recently, been the most widely used schedule of 5-FU administration in the United States and the UK for patients with colorectal cancer. The 'Mayo Clinic regimen' involves 5-FU, given in combination with low dose leucovorin (folinic acid), usually on an outpatient basis, over five consecutive days every 4-5 weeks, for six treatment cycles (Poon et al, 1989). This regimen has been found, in prospective randomised controlled trials comparing its use with single agent 5-FU, to significantly improve response rates (Erlichman et al, 1988; Doroshaw et al, 1980; Figueredo et al, 1997; O'Connell et al, 1997), yet fewer trials have shown an overall survival advantage over 5-FU alone (Advanced Colorectal Cancer Met-Analysis Project, 1992). An earlier randomised controlled trial comparing the 'Mayo Clinic regimen' (monthly treatment) with the 'Roswell Park regimen' (weekly treatment), concluded that the 'Mayo regimen' had a

superior therapeutic index, based on similar response rates, lower costs, and less need for hospitalisation (Buroker et al, 1994).

There are a number of disadvantages of the 'Mayo Clinic regimen', however, including the inconvenience and perhaps, financial burden for patients who have to attend the clinic for 5 consecutive days each cycle as well as the increased resource requirements in terms of staff and pharmacy preparation of the drug (Craven, 2005). Furthermore, despite the fact that the 'Mayo Clinic regimen' was the treatment of choice in the adjuvant treatment of patients with colorectal cancer at the start of this study (NICE, 2004), the findings from some recent clinical trials investigating the efficacy and safety of newer chemotherapeutic agents such as Capecitabine, and Oxaliplatin, and the use of targeted therapies question the continuing use of the 'Mayo Clinic Regimen' in the future treatment of patients with colorectal cancer.

2.6.5 Newer Treatment Options

Capecitabine is a form of 5-FU given orally rather than intravenously, has been found to have a an equivalent time to disease progression and survival rates yet greater response rates when compared with 5-FU and leucovorin (LV) (5FU/LV - the Mayo Clinic Regimen) (Hoff et al, 2001; Van Cutsem et al, 2001; Twelves et al, 2005), and is associated with an improved safety profile (Twelves et al, 2005), greater convenience for patients and healthcare staff (Waterston and Cassidy, 2005), and greater economic savings (Di Costanzo et al, 2006). Other examples include Oxaliplatin given in combination with 5-FU/LV (the combination is known as FOLFOX), and Irinotecan, which have been shown in clinical trials to improve tumour response rate (de Gramont et al, 2000; Goldberg et al, 2003), disease free survival (Andre et al, 2004; Hickish et al, 2004; de Gramont, 2005; Wolmark et al, 2005), median survival (Rougier et al, 1998), and overall survival (Saltz et al, 2000; Goldberg et al, 2003).

Research has also begun to investigate the use of targeted therapies such as monoclonal antibodies, for example Bevacizumab and Cetuximab. Monoclonal antibodies are antibodies that can recognise and bind to tumour antigens or tumour receptors with the purposes of destroying tumour cells, halting tumour cell growth and inhibiting the processes required for cell division, and can target and carry other therapies such as radiotherapy, to tumour cells (Batchelor, 2006). Their use has so far been found to improve response rates and overall progression free survival in the first line treatment of patients with metastatic colorectal cancer (Hurwitz et al, 2004; Saltz et al, 2007), have been found to be well tolerated by patients (Andre et al, 2007; Geissler et al, 2007). At present in the UK, however, Bevacizumab and Cetuximab are not recommended for use in the first or second line treatment of patients with metastatic colorectal cancer (NICE, 2007).

2.6.6 Organisation of Cancer Care Services

Traditionally, chemotherapy was administered to patients as an inpatient based treatment, requiring them to be hospitalised for several days. Changes in the delivery and organisation of cancer services in recent years have however, altered the ways and the environments in which cancer treatments are delivered. The growth in ambulatory cancer care (McCaughan and Thompson, 2000; Fitzsimmons and Middleton, 2006), means that many patients now receive their chemotherapy treatment on an outpatient basis, which for many patients negates the need for hospitalisation during administration of their treatment. There has also been a growing interest in self-administered home-based chemotherapy infusional treatment. This has become possible as a result of the introduction of continuous and portable infusion devices (Kelly et al, 2004).

Owing to the small number of studies in this area, patients' experiences of, preferences towards, and the outcomes of, home-based chemotherapy treatment are unclear and it is not yet standard practice in the delivery of chemotherapy treatment. Three recent qualitative studies have, however, suggested that patients may be more satisfied in receiving their

treatment at home, rather than in the hospital, and may be more likely to comply with treatment and treatment recommendations (Borras et al, 2001; Taylor, 2001; Kelly et al, 2004). It has also been suggested that home-based treatment may be an appropriate option for elderly or psychologically distressed patients as it means they can receive their care at home (Taylor, 2001) and can cause less disruption to patients' daily lifestyles (Monalto, 1996; Kelly et al, 2004). Furthermore, home based treatment may prove to be a safe and cost effective option that may enhance patient control and independence during treatment (Malone et al, 1986; Johansson et al, 2005), however this remains a contentious issue in need of further evidence before it can become recommended practice.

Some concerns around home based treatment relate to the need to have policies and procedures in place, and education for health professionals, to effectively support a service of this nature (Gavin et al, 2004), whilst Kelly et al (2004) reported that patients typically depend on health professionals to manage the adverse effects of treatment, and subsequently, may question their abilities to do this for themselves. Such changes in the organisation of cancer services can greatly influence patients' experiences of treatment and, subsequently, have implications for their self-care. This is discussed further in section 2.7.

2.7 Implications for Self Care

2.7.1 Adverse Effects of Chemotherapy

Owing to the systemic nature of chemotherapy, it is not just cancer cells that are affected by the drugs but also normal, healthy cells within the body (Holmes, 1997). It is these effects on normal cells that are frequently referred to as the side effects of chemotherapy (Holmes, 1997). Characteristically, chemotherapy drugs have a narrow therapeutic index and commonly cause toxicity in rapidly proliferating cells such as the bone marrow, gastrointestinal mucosa, hair follicles and gonads (Holmes, 1997) and owing to the variety of cells they affect, manifest themselves in different ways (Table 2.3).

| Toxicity | Potential effects | |
|-------------------|--|---|
| Haematological | - Anaemia - Thrombocytopenia | - Neutropenia - Fatigue |
| Gastrointestinal | - Nausea and vomiting - Mucositis | - Diarrhoea - Constipation |
| Dermatological | - Alopecia | - Hand-foot syndrome |
| Neurological | - Muscle weakness - Loss of balance and strength | - Loss of sensation |
| Renal and Bladder | - Kidney failure | - Haematuria |
| Organ | - Cardiac arrhythmias - Heart failure - Pulmonary toxicity | - Pulmonary fibrosis - Hepatotoxicity - Hepatic failure |

Table 2.3: Summary of the common toxicities and effects caused by chemotherapy treatment (Coward and Coley, 2006)

2.7.2 Adverse Effects of Chemotherapy for Colorectal Cancer

The adverse effects of chemotherapy treatments are dependent upon the drug given, the dose and route of administration, and the patient's age and general health prior to starting (Coward and Coley, 2006). The main toxicities of 5-FU based regimens are myelosuppression, mucositis, diarrhoea, and nausea and vomiting (Nicum et al, 2003), and more rarely, cardiac and neurologic effects (Nicum et al, 2003). Despite the fact that newer agents such as Oxaliplatin and Irinotecan are providing the focus for the future treatment of patients with colorectal cancer, the side effect profile still appears to favour the Mayo Clinic Regime. The major side effects associated with Irinotecan-based regimens are severe diarrhoea and neutropenia (Saltz et al, 2000) and an increased risk of severe neutropenia and neurotoxicity is associated with Oxaliplatin based regimens (Andre et al, 2004; de Gramont, 2005). The use of oral Capecitabine negates the complications and inconvenience of having an intravenous treatment and it has been found to be generally associated with fewer side effects (Viale et al, 2005). However, there is one exception to this as patients are at an increased risk of experiencing a potentially severe and dose limiting inflammatory condition affecting the palms of the hands and soles of the feet, called plantar-palmer syndrome (hand-foot syndrome) (Viale et al, 2005).

2.7.3 The Importance of Self Care

The previous discussions have highlighted that chemotherapy for colorectal cancer can have some serious adverse effects, which if not promptly and appropriately managed, can lead to further adverse effects, and in some cases can be life threatening. Furthermore, these adverse effects can sometimes lead to patients stopping treatment earlier than expected (Holmes, 1997; Dodd and Miaskowski, 2003). This is compounded by the increasingly toxic side effect profiles, associated with treatments such as Irinotecan and Oxaliplatin, which as discussed are likely to play a large role in the future treatment of patients with colorectal cancer. The implications of this for patients' self care and thus, the need to encourage patients to participate in their self-care have never been more crucial.

Patients receiving chemotherapy must be closely monitored for adverse effects (Holmes, 1997) yet it is no longer feasible for health professionals to be able to continuously do this since the majority of chemotherapy is now given on an outpatient basis, and interest is growing in the use of oral (Bedell, 2003) and home-based treatment by patients in their own homes (Kelly et al, 2004; Johansson et al, 2005). In fact, Bedell (2003) maintains up to 20-25% of all chemotherapy drugs given in the future, will be given orally. Such interest has huge implications for patients in relation to their self-care. The increasing interest in self administered home based and oral chemotherapy, means fewer visits to the cancer centre are required (Gerbrecht, 2003). Hence, this requires that patients learn to become competent and confident in safely handling and administering their treatment (Gerbrecht and Kangas, 2004), and learn when it is necessary to discontinue or suspend their treatment (Faithful and Deery, 2004). Furthermore, like all patients receiving chemotherapy, it is important for them to learn how to recognise changes in their side effect experiences and respond to these with timely and appropriate self-care actions or seek further medical advice (Chau et al, 2004; Faithful and Deery, 2004; Gerbrecht and Kangas, 2004).

There are few studies on patients' perceptions and experiences of home based and oral chemotherapy treatments. Two qualitative studies in patients receiving home based treatment did reveal that particular attention must be given to educating patients and encouraging and supporting their involvement in self care. A small interview study about home-based treatment with patients (n=5) with colon cancer (Kelly et al, 2004), identified that patients were concerned about the use of home based treatment as they trusted health professionals to manage any adverse effects that they experienced and felt that they wouldn't know how to manage these themselves. Furthermore, Johansson et al (2005), in their interview study with 12 patients with multiple myeloma, found that the use of home-based treatment increased anxiety in some patients, however, one patient did report that the use of home based treatment enabled them to participate more actively in their self care. Although, these studies are small, their results are valuable for identifying patients' experiences and importantly, patients' self care needs. This is important for determining how patients wish to be supported to participate in their self care. Further consideration of the increasing drive towards promoting patients' involvement in self care and how this can be effectively supported though a patient focussed approach is considered in the following chapter.

2.8 Overall Summary of Chapter

The discussion in this chapter has considered the use of chemotherapy treatment in the management of colorectal cancer and in particular, has highlighted the changes that have taken place in relation to the nature of chemotherapy and its' mode of delivery for patients with colorectal cancer and the changes that have affected the organisation of cancer services over the past decade. The introduction of new and complex treatment options for patients with colorectal cancer, which frequently involve the use of multiple combinations of chemotherapeutic drugs or the use of oral chemotherapies, and the current provision of care being focussed within the community and outpatient based setting has implications in terms

of patients' experiences of living with, and being treated for, colorectal cancer as well as their self care needs and behaviours.

The following chapter considers the nature and importance of self care, its theoretical and conceptual backgrounds and the increasing role for self care in light of the government's focus on the management of long term conditions within current health policy. The chapter also considers the impact of involving patients in self care, the perceptions of patients and health professionals towards self care, and the evaluation of current strategies to promote and support the involvement of patients undergoing treatment for cancer in self care.

Chapter 3 Self Care

3.1 Introduction

The previous chapter considered the changes which have taken place in the use of chemotherapy treatment for patients with colorectal cancer over the past few decades, and in doing so, highlighted the subsequent importance of patients' involvement in their self care. The following chapter considers the nature of self care in more detail, beginning with a discussion on the difficulty in defining self care, its scope and boundaries, and a discussion of its theoretical background. The chapter then considers the role of self care within the current UK political climate and the evidence of its impact on outcomes in patients with cancer, as well as its economic impact. Finally, given the drive towards encouraging involvement in self care in the UK, the chapter discusses strategies to promote and support patients' involvement in self care, with particular emphasis on the need to acknowledge the individuality of each patient and how their unique experiences, perceptions and beliefs shape their involvement in self care.

3.2 What is Self-Care?

3.2.1 Complexities in Defining Self Care

The term self care is often associated with a lack of theoretical clarity and confusion. This is because the scope and boundaries of self care are difficult to define since many interpretations of the term exist (Soderhamn, 2000; Barlow et al, 2002; Clark, 2003). It is frequently viewed as a spectrum starting from the individual responsibility people take in managing the daily choices that they make in relation to their lifestyle, maintaining their health and preventing illness (Chambers, 2006). Next on the continuum are those activities which are associated with the treatment of minor ailments (Scottish Executive, 2005a; Porteous et al, 2007), which form the greatest part of individuals' self care efforts (Porteous et al, 2007). Finally on the continuum, is the idea of shared care (Chambers, 2006) for example, in the management of long term conditions which frequently require self management choices to be made by patients but with some level of support from health

professionals. Hence, this spectrum demonstrates the difficulties in defining self care since it can be associated with both a medicalised ideology in maintaining a healthy lifestyle and managing the physical effects of illness yet it can be associated with a broader, socialised ideology in relation to the every day lifestyle choices that people make in relation to physical and social functioning (Bury and Pink, 2005; Chambers, 2006). Furthermore, as illustrated here, it is a process which can be viewed as occurring with or without professional assistance (Chambers, 2006). Further confusion exists in its similarities with the use of other terms (Curtin and Mapes, 2001; Lorig and Holman, 2003; McGowan, 2005), such as self management, self management support and self help and as a result, there is much heterogeneity and overlap between the use of these terms.

3.2.2 Definitions of Self Care

Several definitions of self-care have been proposed over the past few decades which highlight the broad spectrum of activities which self care seems to encompass. Levin et al (1977, p11), state that self care is *'the process whereby patients deliberately act on their own behalf in health, promotion, prevention of illness, and the detection and treatment of health deviations'*. Orem (1995, p104), one of the most notable nursing theorists in the area of self care, states that self care is *'the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health and well-being'* and that self care is *'an adult's continuous contribution to his or her continued existence, health and well being'* (p104). The definitions proposed by Levin et al (1977) and Orem (1995) clearly acknowledge that the nature of self care encourages individuals to adopt responsibility for undertaking their own self care but also highlight the spectrum of activities considered to fall within the sphere of self care.

In reflecting the earlier discussion on the medical and social ideologies associated with self care, the Department of Health (2005a, p5) broadly defines self care as *'the actions individuals and carers take for themselves, their children, their families, and others to stay*

fit and maintain good physical and mental health, meet social and psychological needs, prevent illness or accidents, care for minor ailments and long term conditions, and maintain health and well-being after an acute illness or discharge from hospital.' Although, the definitions presented thus far appear to view self care as occurring without professional assistance, Levin and Idler (1983, p181) have acknowledged that in carrying out self care '*individuals are informed by technical knowledge and skills derived from the pool of both professional and lay experience.*' Hickey et al (1986) also proposed that self care is interactive with healthcare professionals, rather than being independent of professional care, whilst Orem (1995) too stated that a large part of self care includes knowing when to seek medical advice and participating in interactions with health professionals.

The definitions presented above highlight that it would indeed be possible to justify the inclusion of nearly all health promoting and illness prevention activities, and actions taken in response to illness, within the spectrum of self care. Hence, they do little to lessen the ambiguity and confusion that exists around the use of the term self care and its nature and scope. For the context of this thesis and the current study, it is important to define self-care in relation to patients' receiving chemotherapy treatment. Hence, the literature revealed few definitions of self care that were specific to patients undergoing treatment for cancer, however, Musci and Dodd (1990) proposed a definition of self care as relating to the actions that individuals carry out in response to the side effects of cancer and its treatments and hence, this was subsequently adopted for the purposes of guiding the current study. Musci and Dodd (1990) maintain that '*patients who practice self care may engage in self observation, recognise and label symptoms, and judge their severity, assess and choose treatment options, and evaluate the effectiveness of self care*' (p395). The importance of this definition lies in its specificity to patients receiving treatment for cancer and thus, provides the context for the following discussion around self care for patients with cancer and for the current research study. It is also important as it explicitly describes how patients

can become involved in self-care; taking control and responsibility for self care, learning to develop a critical awareness and understanding of the nature and implications of treatment-related side effects, and learning to develop a high level of patient expertise with regards to the choice, implementation and evaluation of, self care skills and actions. This definition was used to inform the development of the design of, and methods used in, the study and is returned to for further discussion in Chapter 12.

3.2.3 Central Themes of Self Care

Although the previous discussion has highlighted the different focus of each of the definitions presented above, all of the definitions highlight several key themes that can be considered central to the concept of self care. The first of these is the idea of the patient being encouraged to take a more active role in, and a greater level of control over, their self care. As Rodgers et al (1999) acknowledged, self care transcends the idea of patients as dependent, customary recipients of health services to one where patients become a provider of a large part of their own care. Ultimately, the choices for self care are within the control of the patient, rather than for example, the health professional (Rodgers and Hay, 1998).

The second theme is the idea of self care, occurring not in isolation from health professionals' provision of care, but in collaboration with health professionals. Self care is often seen as the antithesis to formal care delivered by health professionals (Dill et al, 1995) however, self care should be seen as an approach which requires and promotes a greater level of collaboration between patients and health professionals (Paterson and Sloan, 1994; Rodgers and Hay, 1998; Kolbe, 2002; Redman, 2005) across primary, secondary and community care settings (Chambers, 2006). In particular, it is an approach which should acknowledge the importance of actively listening to patients about why, when and how they self care (Ryan et al, 2007) and which should appropriately guide and support patients in their self care practices (Richardson and Ream, 1997; Rodgers and Hay, 1998; Koch et al, 2004).

The importance of these themes are considered within the following discussion on the theoretical and conceptual background to self care.

3.2.4 Theoretical and Conceptual Background to Self Care

Theoretical models are considered to be important for understanding the concept of patients' experiences of illness and symptoms, the processes by which they choose to manage symptoms and become involved in self care, and the factors that influence their choice of self care strategies and their effectiveness in influencing outcomes (Fu et al, 2004). A number of theories and conceptual models, rooted in different disciplines, such as nursing, psychology and the social sciences, seem relevant to the concept of self-care, however, there are few which have been specifically posited as a model designed to underpin self-care research and self care in clinical practice and few which have been empirically tested for their utility. Fu et al (2004) recently identified five theoretical or conceptual models central to the idea of self care and symptom management. These included the Self Care Model (Orem, 1991; 1995), the Conceptual Model for Symptom Management (Larson et al, 1994; Dodd et al, 2001), the Common Sense Model (Leventhal et al, 1984, 1997, 2001), the Symptom Interpretation Model (Teel et al, 1997) and the Theory of Unpleasant Symptoms (Lenz et al, 1995; 1997). These models appear to be grounded within the nursing and psychology literature bases. The researcher was unable to identify any self care models from an additional search of the social science literature.

The Self Care Model (Orem, 1991; 1995) focuses on determining the extent of one's ability to carry out self care for themselves and thus, the extent to which they require nursing care to help them develop or regain their capacity for carrying out self care. The Conceptual Symptom Management Model, developed by Dodd et al (2001), focuses on the subjective symptom experiences of individuals and the factors influencing this, and their symptom management strategies and symptom outcomes. The Common Sense Model, or Leventhal's Self Regulation Model (Leventhal et al, 1984, 1997, 2001) as it is also known, originated

from studies of compliance behaviour and theorises that the perception of fear and threat resulting from the experience of a symptom are determining factors in the initiation of one's self care and coping strategies (Fu et al, 2004). The Symptom Interpretation Model (Teel et al, 1997) postulates that an individual experiences, receives and recognises a stimulus from a symptom and makes a decision about how to manage that symptom (Fu et al, 2004). Finally, the Theory of Unpleasant Symptoms (Lenz et al, 1995; 1997) was developed based on the assumption that commonalities exist among symptoms and that the same factors that influence symptom experience lead to similar interventions effective in alleviating more than one symptom (Fu et al, 2004). Since there is little published literature on the two latter models (the Symptom Interpretation Model and the Theory of Unpleasant Symptoms), the following discussion concentrates on the focus and components of the remaining three models identified by Fu et al (2004); the Self Care Model (Orem's Model of Self Care), the Conceptual Symptom Management Model (the University of California, San Francisco (UCSF) School of Nursing Symptom Management Model), and the Common Sense Model (Leventhal's Self Regulation Model), and considers how these relate to the focus of the current research study. A summary of this discussion is provided in Table 3.1

3.2.4.1 The Self Care Model

Orem's Model of Self Care (as shown in Figure 3.1) is perhaps the most well known model of self care within the field of nursing and originated in the late 1950s as a means of guiding nursing practice, and generating nursing knowledge and nursing theory (Orem, 1995). In developing the model, Orem proposed four patient-related concepts which include *self care*, *self care agency*, which is the capacity of the individual to carry out their own self care; *self care demand*, which is the necessary self care actions needed to meet an individual's self care needs; and *self care deficit*, which exists when an individual can no longer meet their self care needs and thus, identifies the need for nursing care (Orem, 1995).

Orem (1995) also distinguished three types of abilities which are considered to be essential for enhancing patients' capacity to self-care (self care agency) and thus, for enabling them to carry out self-care. These abilities are classed as; i) foundational capabilities, which are general abilities of the person that are not specific to self care, for example, intellectual ability, perception and memory; ii) power components, which are abilities that enable one to engage in self care such as reasoning, motivation and decision making ability; and iii) abilities that relate directly to performing the operations of self care, for example, preparing for and monitoring self care actions (Orem, 1995). In addition, Orem identified that self care agency and thus, self care behaviour, can be influenced by a wide range of factors which she refers to as basic conditioning factors and include age, gender, culture, environment, family and healthcare systems (Orem, 1995).

Given that the intention of the model is to guide nursing care, Orem (1995) identified three nursing systems based on the capacity for patients to perform self care and thus, the extent to which they require nursing care (Orem, 1995). These systems range from wholly compensatory, where nurses provide total patient care, to an educative-supportive system, where patients are guided and supported by nurses to participate in self care (Orem, 1995).

The various components of the model (including, the four patient-related concepts and the three nursing systems) are depicted in Figure 3.1.

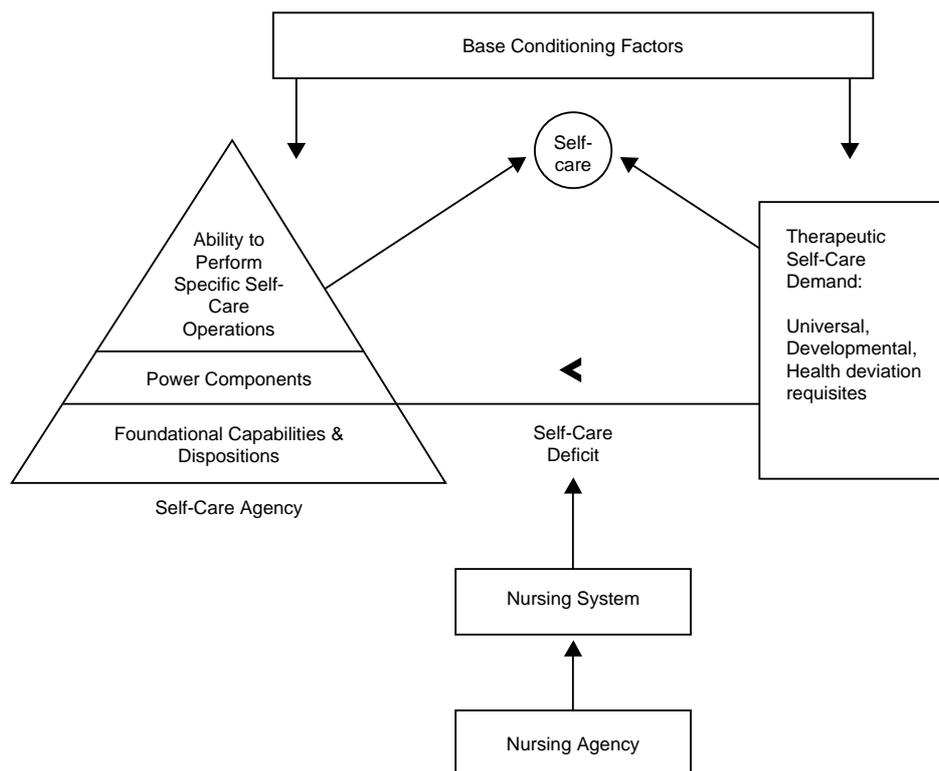


Figure 3.1: Orem's Model of Self Care (Orem, 1995)

The individual components of, and the relationships between, the components of Orem's Model of Self Care have been supported in a number of studies (Dodd and Dibble, 1993; Moore, 1993) and the theory has been applied across a spectrum of health promotion (Hartweg, 1993; Moore, 1993) and illness management activities in patients with a range of different conditions including end stage renal disease (Horsburgh, 1999), diabetes (Frey and Fox, 1990), cardiac conditions (Utz et al, 1990; Utz and Ramos, 1993; Artinian et al, 2002), fatigue (Rhodes et al, 1988) and in patients with mental illness (Harris, 1990; Hamera et al, 1992). However, although the model has also been well used in studies of patients with cancer (Dodd, 1982, 1983, 1987, 1988; Hiromoto and Dungan, 1991; Oberst et al, 1991; Dodd and Dibble, 1993; Craddock et al, 1999; Williams and Schreier, 2004), it is difficult to determine from the accounts of these studies the extent to which the model was used to guide the development of the study interventions and hence, fully conclude the clinical

utility of the model in patients with cancer. As the following discussion reveals, the relevance of the model in relation to the focus of the current study can be further questioned.

The focus of Orem's Model of Self Care is to identify the extent to which individuals require nursing care (that is when the individual can no longer maintain continuous self care for themselves) and, therefore, it is the nurse who often delineates individuals' self care deficits rather than the individual themselves. In this sense, it may be suggested that ultimate control for self care within this model actually belongs to the nurse rather than the individual, which was identified in section 3.2.3 as an important theme within the self care approach (Rodgers and Hay, 1998). In addition to this, Orem (1991) identifies that nurses can help individuals by various means including 'acting for or doing for another'. This raises several issues. Firstly, it suggests that the aim of the model is to eliminate an individual's self care deficit which could occur through a wholly compensatory nursing system, in which the nurse provides total care for the patient, and not necessarily through a supportive-educative system, in which individuals are encouraged and guided to carry out self care actions for themselves. Gast (1996) also acknowledges this and thus, it seems that self care is reduced to a function that determines an individual's extent for nursing care, rather than being acknowledged as an empowering and engaging process for individuals. Hence, if the aim of the model is simply to eliminate an individual's self care deficit by any means necessary, it would appear to conflict with the definitions of self care, discussed earlier, which serve to highlight self care as a process whereby individuals attempt to deliberately carry out self care activities on their own behalf to influence their health and well-being.

As a result, the model may in fact create a greater level of dependency on nurses and may erode an individual's confidence to carry out self-care for themselves. Ultimately, the issues raised here question the underlying focus of Orem's Model of Self Care, and in

particular, the extent to which it has been developed for a professional purpose or whether it reflects a patient centred focus. Many of these issues do not appear to have been questioned, however, in the many accounts of research studies which have utilised the model as the theoretical basis for their work.

Although the model recognises that there are many factors which influence patients' self care agency and thus their capacity to carry out self care, it is unclear whether there has been much consideration of factors such as patients' perceptions of control and self efficacy and the extent to which these influence their involvement in self care. Furthermore, it would also seem that patients' perceptions of their symptoms and preferences for self care and the potential complexities associated with carrying out these actions have also not been considered within the model or indeed by those who have utilised it. This is important since these perceptions are factors which are likely to influence patients' choice of self care actions particularly since individuals will hold different perceptions about the same symptoms and different preferences for self care in managing the symptom (Fu et al, 2004). Thus, the model does little to enhance understanding of these patient-focussed factors and their influence on self care and as a result, holds little relevance to the focus of the current study.

3.2.4.2 The Conceptual Symptom Management Model

The University of California, San Francisco (UCSF) School of Nursing Symptom Management Model (as shown in figure 3.2) is a generic, patient focussed symptom management model which is designed to be used by nurses to promote patients' self care symptom management abilities (Larson et al, 1994; Dodd et al, 2001; Voss et al, 2006). The model was initially developed from a practice orientated focus because of the reduced time that nurses are able to spend with patients and because of the need to develop a consistent and effective approach to symptom management that would be relevant and understood by both patients and nurses (Dodd et al, 2001). It is based on patients' self

report of symptoms since this is considered to be the gold standard of symptom reporting (Dodd et al, 2001) and assumes that a symptom does not need to be experienced before symptom management strategies can be implemented. Thus, it also promotes the idea of preventative self care where there is the risk of a symptom developing.

According to this model, effective and consistent symptom management relies on three dimensions; symptom experience, symptom management strategies and symptom outcomes. The symptom experience includes the individual's perception of a symptom, evaluation of the meaning of a symptom and their response to a symptom. The assessment of the nature of a symptom is then followed by a dynamic process of symptom management whereby the individual attempts to manage the symptom by various strategies to bring about a desired outcome. This can involve self monitoring, self care, self regulation or self treatment (Dodd et al, 2001). Finally, symptom outcomes such as functional status, emotional status, and quality of life emerge from the symptom management and experience processes. The model also recognises some of the wider influences of symptom management as being related to the person including, demographic, psychological, sociological variables and variables related to the health and illness state of the individual which may affect symptom experiences and symptom management strategies, as well as the environment, encompassing physical, social and cultural variables (Dodd et al, 2001).

These dimensions and components are depicted in Figure 3.2.

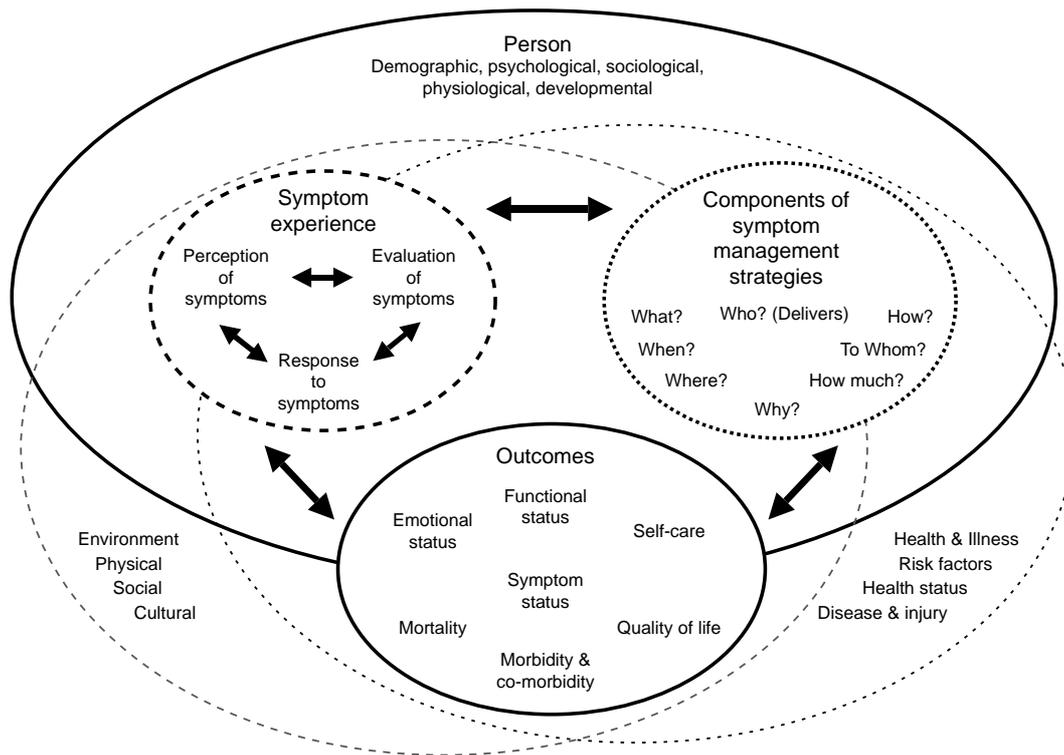


Figure 3.2: The Conceptual Symptom Management Model (Dodd et al, 2001)

Unlike Orem’s model, the strengths of this model lie in its patient focus, in particular, in its attempts to understand symptom experiences and management strategies from the patients’ perspective, and its comprehensive consideration of the many factors which can influence patients’ symptom and self care experiences. Therefore, this model seems more relevant to the current study. The model also takes cognisance of the complexity of the process of self care and those factors which influence patients’ attempts at carrying out self care. Furthermore, it would seem to be particularly relevant to patients with cancer given that it has been developed by researchers, such as Marilyn Dodd, who have expertise in cancer care and symptom management.

However, as yet the model is still in its infancy and still at the stage of being refined, requiring further testing and a richer description of how it applies to patients with cancer. Furthermore, like Orem’s Self Care Model, the Conceptual Symptom Management Model

can be criticised for assuming that all individuals have the desire to carry out self care. Existing research, however, has identified that many individuals do not become involved in their self care either because of a lack of desire or ability to do so (Richardson and Ream, 1997; Ni et al, 1999). As a result the applicability of both Orem's model and the conceptual symptom management model to those individuals who choose to remain dependent on healthcare professionals is doubtful. Furthermore, it is unclear from the current reports of the model (Larson et al, 1994; Dodd et al, 2001; Voss et al, 2006), the extent to which influences such as perceived control and self efficacy have been considered within the model and their potential influence on patients' self care thus, questioning the relevance of this model to the focus of the current study.

3.2.4.3 The Common Sense Model

One such model which does consider the influence of patients' perceptions of control on behaviour is the Common Sense Model, or Leventhal's Self Regulation Model (Leventhal et al, 1984, 1997, 2001) as it is also known. This particular model (as shown in Figure 3.3) posits that individuals develop their own common sense beliefs or perceptions about their illness which they use to make sense of and understand their illness. It is these perceptions that determine individuals' behaviours and their responses to managing the threat of illness or its effects, and hence, influence their health outcomes. In relation to the current study, for example, this was considered to relate to patients' perceptions of being diagnosed with cancer and undergoing treatment and their perceptions of the treatment-related side effects that they were likely to experience and how they intended to cope with and manage these.

Figure 3.3 demonstrates that there are three broad stages to the model; *representation*, which refers to the individuals' cognitive and emotional perceptions of the illness; *coping*, which involves the development of plans to manage and cope with the illness; and *appraisal*, in which the individual uses specific criteria to gauge the success of one's coping actions in terms of their own abilities to perform the action and also their impact on

desirable outcomes (Leventhal et al, 1986; Leventhal and Cameron, 1987). It can also be seen from Figure 3.3, that individuals' illness perceptions in the representation stage of the model are developed based on five dimensions; *identity* (ideas about the label of the illness and the symptoms that it causes), *timeline* (the duration of the illness – acute or chronic), *cause* (ideas about the likely causes), *consequences* (the effects of the illness on their lives), and *control or cure* (the extent to which the illness can be controlled or cured, by both themselves and others e.g. health professionals).

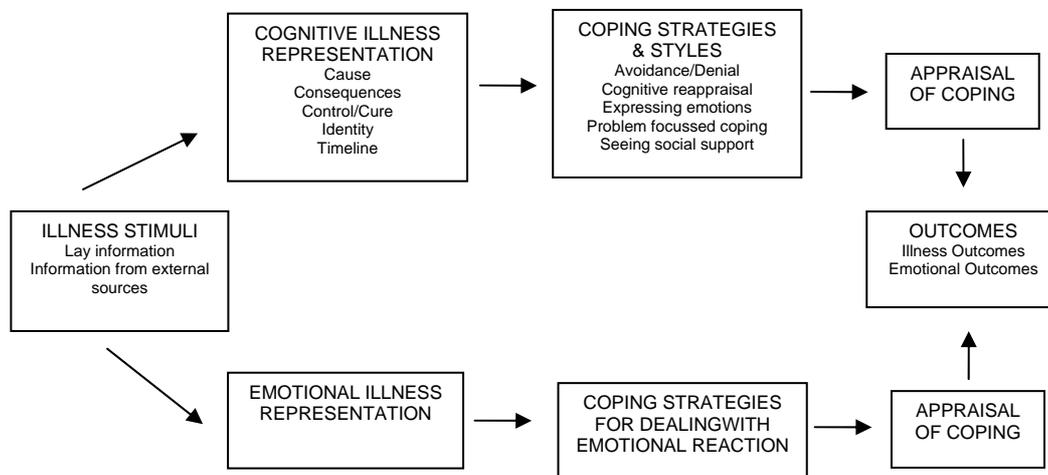


Figure 3.3: Leventhal's Self Regulation Model(Leventhal et al, 1984, 1997, 2001)

There are several aspects of Leventhal's Self Regulation Model (Leventhal et al, 1984 1997, 2001) that made it the framework of choice in the current study. This included its patient focus, its ability to provide an understanding of patients' experiences and perceptions of their illness and its management, the inclusion of components such as, perceived control, which were of interest in this study and finally, the large body of research which supports its utility.

A recent meta-analysis of 45 empirical studies using Leventhal's model of illness behaviour concluded that there was consistent support for the different illness cognition dimensions in patients with different types of illnesses (Hagger and Orbell, 2003). The model has been tested in patients with cancer (Leventhal et al, 1986; Buick, 1997; Cameron, 1997) as well as in a wealth of research in other patients groups showing support for its individual components. Such groups have included patients with diabetes (Griva et al, 2000; Carlisle et al, 2005), multiple sclerosis (Jopson and Moss Morris, 2003), chronic fatigue syndrome (Petrie et al, 1995), epilepsy (Goldsten et al, 2005), systemic lupus erythematosus (Goodman et al, 2005), and in patients recovering from stroke (Johnston et al, 1999a) and myocardial infarction (Petrie et al, 1996; Whitmarsh et al, 2003; MacInnes, 2006). However, since the majority of these studies have employed one off, cross sectional designs, further work, incorporating a qualitative component would be useful (as in the current study) to contextualise existing research and offer an understanding of realities of patients' lived experiences for example, in understanding why patients' illness perceptions influence their health behaviour. Further work incorporating the use of a longitudinal design (as in the current study), rather than cross sectional would also be useful for understanding how patients' illness perceptions change over time and how these changes influence subsequent involvement in self care in patients with cancer. The use of the model in this study is returned to in Chapter 12.

Table 3.1 provides a summary of the discipline and focus associated with the three models discussed above and their strengths and weaknesses in relation to the relevance of the current research study.

| Model | Discipline/Focus | Strengths | Weaknesses |
|--|---|--|---|
| Orem's Model of Self Care (Orem, 1991; 1995) | <ul style="list-style-type: none"> - Nursing - Determining patients' capacity for self care, and hence, extent to which they require nursing care | <ul style="list-style-type: none"> - Model has been widely tested, including amongst patients with cancer | <ul style="list-style-type: none"> - Lack of a patient focus - Nurses' determine patients' self care needs and can employ self care actions on behalf of patients too - Fails to acknowledge self care as an empowering process - May erode patients' confidence to carry out self care rather than enhance it - Assumes all patients have a desire to carry out self care - Not clear to what extent perceived control and self efficacy are incorporated into the model - Not clear to what extent patients' perceptions of symptoms and symptom management strategies are incorporated into the model |
| The UCSF Symptom Management Model (Dodd et al, 2001) | <ul style="list-style-type: none"> - Nursing - Subjective experiences of symptoms, symptom management and symptom outcomes | <ul style="list-style-type: none"> - Patient focus - Incorporates many influences of self care, including patients' perceptions of symptoms, symptom management strategies and symptom outcomes - Highlights the importance of preventative self care | <ul style="list-style-type: none"> - Further testing required in patients with cancer - Assumes all patients have a desire to carry out self care - Not clear to what extent perceived control and self efficacy are incorporated into the model |
| The Self Regulation Model (Leventhal et al, 1984, 1997, 2001) | <ul style="list-style-type: none"> - Psychology - Coping responses to perceived threat of illness | <ul style="list-style-type: none"> - Patient focus - Has been tested in patients with cancer - Wealth of empirical support in relation to physical and emotional outcomes, adjustment and coping, and adherence - Acknowledges that individuals' illness perceptions are different influenced by factors such as, the nature of the illness itself, symptoms, culture - Factors including perceived control and emotional responses are incorporated into the model | <ul style="list-style-type: none"> - Further qualitative research needed to contextualise the reality of patients' lived experiences - Further longitudinal research needed on how patients' illness perceptions change over time and how these changes influence patients' involvement in self care |

Table 3.1: Focus, components and strengths and weaknesses of self care models in relation to the current study

Having highlighted the nature of self care and its theoretical underpinnings, the following section considers the recent interest in encouraging peoples' involvement in self care from a health policy perspective.

3.3 Interest in Self-Care

Although people carry out self care every day in terms of managing lifestyle choices and maintaining health and well being (Ryan et al, 2007), there has been a renewed emphasis within recent health policy in the UK on promoting a greater level of involvement of people with long term or chronic conditions in their self care in the management of such conditions. Policy support for self care has been firmly established within a number of published reports such as, *'The NHS Plan'* (Department of Health, 2000), *'The Expert Patient'* (Department of Health, 2001), and most recently, *'Supporting People with Long Term Conditions'* (Department of Health, 2005a), *'Self Care – a real choice'* (Department of Health, 2005b), and *'Our Health, Our Care, Our Say'* (Department of Health, 2006a). A focus on self care has also been encouraged within the Scottish healthcare system with the publication of *'Partnership for Care'* (Scottish Executive, 2003), and most recently, the *'National Framework for Service Change in Scotland'* (Scottish Executive, 2005a) and *'Delivering for Health'* (Scottish Executive, 2005b).

These reports appear to have acknowledged the changing focus of chronic disease management and service provision within the NHS, to one which places a greater emphasis on the management of long term conditions through community and outpatient based care and self care. More generally, political support for self care may also have been influenced by the recent moves towards greater patient and public involvement in healthcare (Hubbard et al, 2005) and the growing evidence base on involving patients in decision making related to their care (Degner et al, 1997; Beaver et al, 1999; Davison et al, 1999, 2004). Such calls reinforce support for a move away from the existing top down model of care characterised by

a 'doctor knows best' attitude amongst health professionals who have done things to, rather than with, patients (Tyreman, 2005), to a culture where patients' subjective experiences are considered an essential contribution to understanding the experience of illness and where patients are respected and encouraged to work together with health professionals to meet their needs.

However, as revealed in the following sections, as yet there is little robust evidence to support the movement towards involving people in self care in terms of patient and economic outcomes thus questioning the strength of the evidence which has been used to underpin the UK's current political stance on self-care. Furthermore, there remains questions about the real, underlying focus of the government's renewed interest in self care and little evidence to support that a move towards increased involvement in self care is welcomed and if, and how, it will be supported by both patients and health professionals. The following discussion considers these issues beginning with the impact of self care and following with a discussion on patients' and health professionals' perceptions towards self care.

3.4 Impact of Self Care

The trend towards encouraging a greater level of involvement in self-care has been met with both enthusiasm and caution (Rodgers et al, 1999). On the one hand, there are likely to be many benefits in involving people in their own self care since self care interventions in people with arthritis (Lorig et al, 1999; Barlow et al, 2000), end stage renal disease (Tsay et al, 2005) and HIV/AIDS (Gifford et al, 1998) appear to lead to clinically important improvements, including improvements in health status (Lorig et al, 1999), reductions in symptom related morbidity (Gifford et al, 1998; Lorig et al, 1999; Barlow et al, 2000) and physical disability (Lorig et al, 1999) and improvements in psychosocial well being (Lorig et al, 1999; Barlow et al, 2000; Tsay et al, 2005). However, as revealed in the following discussions, at present the strength of the evidence which has been used to underpin the

governments' current recommendations in relation to promoting involvement in self care is dubious. Further research would be useful to establish the wider impact of self care. The following discussion considers the existing evidence in relation to outcomes of self care in patients with cancer and the economic impact of self care.

3.4.1 Impact of Self Care in Patients with Cancer

A recent systematic review by Hubbard et al (2007) identified that involving patients with cancer in self care was important for several reasons. In particular, the review identified that patients hold unique knowledge and experience of living with cancer and its effects and, therefore, they can contribute to the effective management of these effects (Hubbard et al, 2007). Furthermore, the shift from hospital to outpatient based care has meant that a greater level of responsibility for managing the effects of cancer and its treatments now falls to patients and their families and, therefore, they should be encouraged to become involved in their self care (Hubbard et al, 2007).

Several self care intervention studies in patients with cancer have also found that a greater level of involvement can improve understanding of the effects of cancer and its treatments (Hagopian, 1996; Benor et al, 1998), and can contribute to reducing the occurrence, severity and associated distress of symptoms (Benor et al, 1998, McDaniel and Rhodes, 1998; Oliver et al, 2001; Given et al, 2004; Miaskowski et al, 2004). Further benefits have been identified including improvements in psychosocial wellbeing, for example, less anxiety and depression (Dodd, 1987, 1988; Benor et al, 1998; Braden et al, 1998; Williams and Schreier, 2004; Ream et al, 2006), as well as enhanced perceptions of confidence and control (Benor et al, 1998; Braden et al, 1998). Involvement in self-care has also been associated with improved coping abilities with which to manage the effects of cancer and its treatments (Ream et al, 2006).

Many of the studies referenced here, and indeed their methodological limitations, are considered in further detail in sections 3.6.1, 3.6.2 and 3.6.3. However, in relation to the strength of the evidence from these studies, several points are important to note at this juncture. Despite their encouraging results, the findings from many of the studies mentioned above make a limited contribution to the current evidence base on the outcomes of self care since, although quantitative in design, several have been conducted in small samples (Dodd, 1983, 1987, 1988; Hagopian, 1996; McDaniel and Rhodes, 1998; Oliver et al, 2001; Williams and Schreier, 2004). Presumably the intention of the design of these studies was to be able to generalise study findings to wider groups of patients with cancer, however, their small sample size (for a purely quantitative study) limits this. Furthermore, several studies have recruited heterogeneous samples of patients with different types or stages of cancer (Dodd, 1987, 1988; Benor et al, 1998; Braden et al, 1998; Oliver et al, 2001; Given et al, 2004; Miaskowski et al, 2004; Williams and Schreier, 2004; Ream et al, 2006), which makes it difficult to determine how factors such as cancer type and stage and severity of disease influence the extent to which patients' are motivated, and able, to become involved in self care. Ream et al (2005) acknowledged that patients may have different self care needs depending upon their stage in the treatment journey, for example, patients beginning adjuvant treatment may have different self care needs from those patients who are undergoing palliative treatment. Thus, owing to the existing level of heterogeneity within study samples it is difficult to determine how patients' self care needs differ across the cancer and treatment journey and who benefits most from being involved in self care. Another point to note is that studies on self care in patients with cancer have predominantly recruited white individuals (Hagopian, 1996; Braden et al, 1998; Oliver et al, 2001; Miaskowski et al, 2004; Williams and Schreier, 2004), with a high level of education (Hagopian, 1996; Oliver et al, 2001; Miaskowski et al, 2004; Williams and Schreier, 2004), which has, therefore, limited the evidence base in terms of the impact of self care amongst people from a diverse range of cultural backgrounds and those with a lower educational status.

The majority of these studies have also originated in America, with only one study being conducted within the UK (Ream et al, 2006) and most were cross sectional and have not involved a great deal of repeated measures nor investigated the impact of being involved in self care beyond five months following the intervention. Hence, this makes it difficult to determine the long term impact of involving patients with cancer in self care. As a result of these limitations, there are notably large gaps in the evidence base and hence, little is known about the long term impact and experiences of self-care in a broad and diverse range of individuals, particularly those living in the UK. Consequently, this is an important area for future research, and further efforts are required to investigate the longer term outcomes of self-care within a UK context.

Hubbard et al's (2007) review also identified that involving patients with cancer in self care was believed to be important for its potential economic benefits, by way of contributing towards a more cost effective healthcare system and promoting more efficient use of resources. Although this is a widely held view (Chambers, 2006) and is likely to be a driver in the government's renewed interest in self care, there is little robust evidence to demonstrate that peoples involvement in self care can reduce healthcare expenditure and promote appropriate service utilisation within the UK, regardless of disease or illness type of the patient. The economic impact of involving people in self care is reviewed in the following section.

3.4.2 Economic Impact of Self Care

Several American-based studies have suggested that involving patients in their self care may contribute to reducing or containing healthcare costs by reducing the number of outpatient clinic visits and medical consultations required by patients (Vickery et al, 1988; Lorig et al, 1999; Chiou et al, 2004) and preventing unnecessary hospitalisations (Lorig et al, 1999). Only one study, originating in the USA, has been identified that specifically attempted to

investigate the economic impact of self care in relation to patients with cancer (Jacobsen et al, 2002). In this particular study, Jacobsen et al (2002) set out to compare the costs (reimbursement costs and the human and capital resources used) associated with a patient self administered stress management training (SSMT) intervention with a professionally-led stress management training (PSMT) intervention in 411 patients with cancer. The findings revealed that the estimated average costs for the SSMT intervention were generally less than those of the PSMT intervention (\$100 less from a payer perspective and \$140 less expensive from a societal perspective). It is important to note, however, that despite these findings direct comparison with other studies is difficult since there were no other cost evaluation studies in patients with cancer identified. Furthermore, the use of differing methods of evaluating costs in different studies may also make comparison with studies in patients with other diseases more challenging (Jacobsen et al, 2002).

Studies in patients, other than those with cancer, have also attempted to evaluate the economic aspect of patients' involvement in self care. A somewhat older study conducted by Vickery et al (1988) found that the use of a self-care manual amongst illness-free individuals, focussing on self care-related decision making, use of medical services and lifestyle advice, resulted in a significant decrease of 15% in total medical visits in a study of Medicare-enrolled families randomised to experimental (n=363) and control groups (n=291). These results are encouraging, however, it should be noted that many participants were lost to attrition (Vickery et al, 1988) and this may have affected the reliability and validity of their results. More recently, a randomised controlled trial on the use of a self-management programme in patients (n=67) with HIV/AIDS, designed to encourage participants to develop their confidence and put their self care skills into practice, demonstrated a significant reduction in the mean number of unscheduled hospital visits in the experimental group from pre to post test (-0.48 ± 0.85 , $z=-2.39$, $p=0.017$) (Chiou et al, 2004). The control group participants also experienced a reduction in unscheduled hospital visits (0.05 ± 0.49 , $z=-$

0/447, $p=0.655$). Although this change was not significant, the reduction seen in both groups may have been a result of the telephone counselling that both groups received, rather than the self care teaching itself. Furthermore, the small number of patients in this quantitative study means that these findings cannot be generalised to other populations with confidence. A randomised controlled trial on the Chronic Disease Self Management Programme (Lorig et al, 1999), in a larger number of patients with chronic diseases (not cancer) ($n=952$), found that those who participated in the programme ($n=561$) were significantly less likely to be hospitalised due to the effects of their disease (mean number of hospital stays were 0.24 at baseline compared with 0.07 at 6 months post test [sd.0.69], $p<0.05$). Again, however, these findings should be treated with caution since the majority of participants were Caucasian and reasonably well educated, limiting their relevance to different groups of individuals. Furthermore, owing to the use of self-report instruments the authors reported that there may have been several occasions where participants underreported hospital visits (Lorig et al, 1999) hence, the reliability of these findings are uncertain.

The studies discussed thus far were all conducted in the USA, where care organisations differ greatly from the NHS in the UK, therefore, the relevance of these findings to UK populations is questionable. The only UK study that was identified, conducted by Robinson et al (2001), suggested that there may be potential for economic savings by promoting greater involvement in self-care. In this study, a randomised controlled trial design was used to evaluate the economic impact of a guided self management programme for patients ($n=203$) with ulcerative colitis in four hospitals in England (Robinson et al, 2001). The findings demonstrated that when compared with the control group, experimental group patients made significantly fewer outpatient visits (0.9 vs 2.9, difference 2.0 [sd 1.6-2.7], $p<0.0001$) and general practitioner visits (0.3 vs 0.9, difference 0.6 [sd 0.2-1.1], $p=0.0006$) during the intervention period. However, the study was not sufficiently powered to detect differences in hospital admission rates although travel cost savings were identified between the patients in

the experimental group when compared with the control group (£0.86 (sd 3.41), vs £8.92 (sd 18.30) per patient) and there were reductions in the amount of time spent with doctors between patients in the experimental and control groups (1hr (sd 2.95) vs 6.2hrs (sd 7.1) per patient) as a result of the self management programme.

The most recent analysis on the existing evidence on the economic impact of self care, however, comes from a systematic review on the cost effectiveness of interventions to support self care (Richardson et al, 2005). In this review, the authors concluded that the evidence from 39 economic evaluations of self care support interventions was of a poor quality and thus, the current evidence base does not support the view that self care has economic benefits (Richardson et al, 2005). Richardson et al (2005) noted several aspects that have weakened the accumulation of robust evidence on the economic impact of self care including, the use of narrow definitions of costs which often fail to include costs such as patients' out of pocket expenses, travel expenses and time off work, the failure of studies to compare the cost effectiveness of self care with an appropriate alternative, and the use of short term follow up periods, for example, of less than 1 year, meaning that the long term economic impact of self care is unclear. Therefore, although this discussion has highlighted the findings from the one existing UK economic evaluation of self care, given the methodological weaknesses in the evidence base, the current stance within UK policy supporting self care for its economic benefits (Department of Health, 2005b) seems rather premature.

The discussions in section 3.4.1 and 3.4.2 acknowledged that, despite some encouraging findings, studies on the impact of involving people in their self care have predominantly been carried out with samples which are limited in their potential for generalisability because of their sample size, and lack of diversity in terms of socio-cultural and demographic composition. Furthermore, the predominance of quantitative methodologies and

heterogeneous samples means that such studies fail to determine how patients' self care needs differ across the cancer and treatment journey and who benefits most from being involved in self care and subsequently, fail to contribute towards the accumulation of a qualitative evidence base on perceptions towards self care. Studies of the economic impact of self care are limited by failures to include cost comparisons, to adopt a wide definition of costs and to investigate the longer term economic impact of self care. Furthermore, the studies referred to in sections 3.4.1 and 3.4.2 have rarely been conducted in the UK or with a UK context in mind.

Therefore, despite strong support for self-care in the UK within current health policy, the robustness of the current evidence base is weak in relation to the health and economic outcomes associated with involving people in self-care. Subsequently, its relevance within a UK context is at present, questionable and before policy recommendations can be fully implemented further research on the health and economic outcomes of self care in large, diverse samples within the UK is needed. In addition, despite the increasing political support for self care there was little evidence identified to suggest that greater involvement in self care is a move that is welcomed by patients and health professionals and little guidance to suggest how such involvement should be encouraged and supported in practice. The following discussion considers these issues in relation to health professionals' and patients' perceptions towards self care.

3.5 Perceptions Towards Self Care

In spite of the increasing moves towards supporting a greater level of involvement in self care by patients, there is still some dubiety surrounding the concept of self care amongst patients and health professionals and differing beliefs on the value of self care and expectations as to what an increased role in self care may involve for patients and health professionals. The following discussion begins by considering the literature on health professionals' perceptions

towards such moves for greater involvement in self care and its drivers before considering the current evidence base on patients' perceptions of self care and what this may involve.

3.5.1 Perceptions of Health Professionals

Much has been written on the developing role of 'expert patients' (Wilson, 2001; Tattersall, 2002; Shaw and Baker, 2004; Badcott, 2005; Tyreman, 2005; Mayor, 2006; Plews, 2006), fuelled by the creation of the 'Expert Patient Programme' (Department of Health, 2001), which is specifically designed to encourage patients to take responsibility for their self care and develop their self care knowledge and skills. However, support for a greater level of involvement in self care may be hindered by health professionals' concerns about the creation of 'expert patients'. The literature identified that many health professionals question the value of self care and whether patients are truly ready, competent and willing to accept a role which assumes a greater level of responsibility for managing their self care and their health (Jones et al, 2000; Thorne et al, 2000; Wilson, 2001; Bury, 2004a; Prior, 2003; Rodgers et al, 2005). Others view such moves towards greater involvement in self care as a threat to their professionalism (Ryan et al, 2007), identified more so amongst nurses (Wilson et al, 2006), and feel reluctant to relinquish control to patients (May, 1995; Pill et al, 1999). In a study of health professionals' (n=100) perceptions (including, doctors, nurses, and allied health professionals), Wilson et al (2006) identified that nurses' resistance towards self care arose from fears of litigation, concerns about the effective management of the patient should self care be relied upon, a desire to maintain their professional autonomy and authoritative knowledge and the challenge of working towards a self care approach within an already tightly bound bureaucratic healthcare system. They also identified that nurses experienced problems with role boundaries and definitions and a lack of autonomy, perhaps stemming from the quest for nursing professionalism and the perceived dominance of medicine, in comparison to the other health professionals who were able to quite quickly articulate their

areas of expertise in relation to the patients' overall management and perceived their autonomy to be untarnished (Wilson et al, 2006).

Tyreman (2005) further criticises the '*The Expert Patient Programme*' for failing to be clear about what the term 'expert' really refers to and questions whether the programme really has the potential to enhance patient autonomy. The influence of current UK health policy in stimulating a greater level of involvement in self care is, at present, not yet fully known. Further critiques of '*The Expert Patient Programme*', which is specifically designed to encourage patients to take responsibility for their self care and develop their self care knowledge and skills, have claimed that such initiatives have retained a 'top-down' approach (Bury, 2004b) and, therefore, have done little to quash the paternalism and dependency that earlier health policies created in the 1980's and early 1990's (Wilson, 2001). Poulton (1999) also questioned whether rather than creating a well informed, self caring individual these policies and initiatives have lead to the creation of a more demanding individual who, as a result, may actually become a greater user of healthcare services.

Resistance towards adopting a self care approach may stem from dubiety and suspicion surrounding the governments' motivations for promoting a greater level of patient involvement in self care. It is questionable whether the governments' interest and support for self care is really focussed on empowering patients and furnishing them with the means to develop their self care skills because it is fundamentally important for them and ultimately will improve their health and well-being, or whether it is a managerial response in an effort to drive down costs and limit healthcare spending, as suggested by Tyreman (2005) in relation to '*The Expert Patient Programme*'. These views support those of Coulter (1999) who claimed that initiatives, seemingly designed to promote involvement in self care such as '*The Expert Patient*', were embraced by policy makers as a means of reducing healthcare costs by reducing the frequency of unnecessary hospital admissions and ensuring that resources are

channelled more appropriately. In Scotland for example, the *National Framework for Service Change in Scotland* (Scottish Executive, 2005a) has explicitly emphasised the importance of supporting the delivery of care in local communities and promoting patients' participation in self-care to reduce the need for hospital visits.

It is also possible that there may be some resistance to adopting these policies since little of what is written in these documents actually details *how* health professionals can encourage and support patients' involvement in self care. No evidence has been identified to substantiate the view that health professionals are currently providing, or willing to provide, patients with the necessary education, support and encouragement to facilitate their participation in self care. However, this may change as further research in this area develops, yet there is some evidence which suggests that health professionals lack an understanding of the factors that influence patients' involvement in self care for example, culture and level of education, and what self care actually involves for patients (Nagelkerk et al, 2006).

Most importantly, however, what seems to be missing from the existing evidence base and within current health policy is a focus on individual patients, the importance of which was highlighted in the discussion around models of self care and is further discussed in the following section. An appreciation of the ways in which individuals' perceptions and experiences shape their desire and abilities for involvement in self care is valuable since policies favouring a blanket approach to promoting involvement in self care such as *The Expert Patient Programme*, have been found to be unlikely to be adopted if they are not relevant to the patients in which their recommendations are intended to benefit (Kennedy et al, 2005). Further consideration of the use of blanket approaches to supporting self care is given in section 3.6.3.

3.5.2 Perceptions of Patients

Since there has been little evidence of a patient focus within previous research on self care and within existing health policy centred around self care, little is known about patients' perceptions of, and attitudes towards, self care. What's more, little is known about the factors which they perceive to influence their involvement in self care as well as the strategies which they consider helpful in encouraging their involvement. Several UK national surveys have recently claimed that many people in the UK are keen to take a more active role in managing the effects of living with a long term or chronic condition (Department of Health, 2005c; Ellins and Coulter, 2005). Despite this, qualitative research conducted in the UK and the USA has highlighted that patients do not adopt a greater level of involvement in their self care for several reasons (Sims, 1999; Riegel and Carlson, 2002; Horowitz et al, 2004). In particular, two studies, one in patients with hypertension (n=49) in the UK (Sims, 1999) and one in patients with heart failure (n=19) (Horowitz et al, 2004) in the USA, identified that contrary to the findings from the surveys above, many patients did not expect to become involved in self care and that they considered the doctor to be the expert and it was him or her that was, therefore, responsible for managing patients' symptoms.

Another study in patients with heart failure (n=26) in the USA (Riegel and Carlson, 2002) identified that many patients did not value their involvement in self care and did not believe that their own self care would actually help to relieve their symptoms. The only study identified which investigated the perceptions of patients with cancer (n=48) in relation to self care was conducted in the USA and reported that patients believed treatment-related side effects to be a necessary part of their treatment for cancer. They expected, therefore, that little could be done about these side effects and that they simply had to be endured rather than actively managed through their own self care (Dodd, 1982). Although these studies cannot be generalised owing to their small samples and in some cases, convenience samples, of patients who are willing to share their personal experiences (Riegel and Carlson, 2002),

collectively they are valuable for providing an insight into how patients' perceptions of their illness and their beliefs about self care can influence their subsequent involvement in self care. These studies highlight the importance of understanding such views in helping to provide guidance and support for patients' involvement in self care however, little attention has been paid to this thus far within existing research on self care.

Further findings have revealed that patients also may perceive there to be a lack of opportunities and support offered to them by health professionals to help them become involved in their self care (Sims, 1999; Scotto, 2005) and questions over whether health professionals will view patients' own self care as legitimate (Stevenson et al, 2003). Scotto's (2005) qualitative study, conducted with patients with heart failure (n=14) in the USA, also identified that health professionals often fail to understand the challenges faced by patients in attempting to follow self care advice. Another study by Jerrant et al (2005) conducted with patients with heart failure (n=19) in the USA, also identified that patients were not made aware of the range of self care support services that may have been available to them. Further studies have identified that there is a lack of self care information, education and training offered to patients to help them become involved in self care (Ni et al, 1999; Hussein and Partridge, 2002; Riegal and Carlson, 2002). However, this may stem from some of the issues discussed in the section 3.5.1 in relation to possible rationales for resisting the move towards self care amongst health professionals.

The discussions in sections 3.5.1 and 3.5.2 have highlighted the importance in understanding peoples' perceptions towards adopting a greater level of involvement in self care. It is important to consider health professionals' perceptions towards self care since they are being heralded within current health policy as the advocates of greater moves towards self care and subsequently, reasons for their resistance towards this move should be considered. However, since it is patients who are being encouraged to adopt a greater level of responsibility for, and

involvement in, self care, it is also important to understand their unique and individual perceptions on the value of self care and their beliefs about and expectations of their increased role in self care. Qualitative research, with a patient-centred focus is useful for acknowledging the individuality of patients and would be valuable for understanding their unique experiences of being involved in self care and what this means to them. Such research is clinically important for helping caregivers and health professionals to collaborate effectively with patients in encouraging those who wish a greater level of involvement in self care (Davidson et al, 2004). The following section considers why an individualised, patient focussed approach is valuable in light of the findings from current interventions designed to support the involvement of patients with cancer in their self care yet, which have often failed to acknowledge the individuality of patients and their perceptions towards self care.

3.6 Interventions to Support Self Care

Interventions designed to provide patients with self care information and education and the provision of structured self management programmes have been identified as central approaches for encouraging involvement in self care (Kennedy and Rodgers, 2001). Relevant, timely and individualised self care information and education is essential for helping patients to enhance their understanding of their illness as well as the value of and the ways in which they can become involved in their self care (Kennedy and Rodgers, 2001). A wealth of literature focussing on patients with cancer living in the UK, USA and China has identified that information on the effects of cancer and its treatments and how to successfully cope with, and manage, these effects is repeatedly identified as a key information need by patients with cancer (Bilodeau and Degner, 1996; Luker et al, 1996; Degner et al, 1997; Mun Lee et al, 2004; Skalla et al, 2004; Finney Rutten et al, 2005). Access to self management programmes, designed to help patients translate their self care knowledge into practical skills which they can use to manage the effects of their illness and which offer emotional support

and help to build patients' confidence, have also been identified as an important means of promoting involvement in self care (Kennedy and Rodgers, 2001).

The following discussion considers some of the many examples of informational and self management interventions that have been carried out in patients undergoing treatment for cancer. The discussion begins with an examination of informational interventions (section 3.6.1) before moving on to consider self management interventions (section 3.6.2) in patients undergoing treatment for cancer. In section 3.6.3, the methodological limitations of these intervention studies, which limit the contribution of their findings to the evidence base, is considered. In particular, this discussion focuses on the fact that there has been little use of repeated measures; longitudinal designs, to confirm whether involvement in self care is sustained over time; and little qualitative investigation to identify patients' preferences on the most appropriate ways of promoting their involvement in self care, their perceptions towards and meanings of their self care, and the ways in which their unique perceptions and experiences shape their involvement in self care.

3.6.1 Informational Interventions

Many studies in patients undergoing treatment for cancer have focussed on supporting involvement in self care through the provision of information and education about treatment-related side effects and self care (Dodd, 1983; 1987; 1988; Walker, 1992; Hagopian, 1996; McDaniel and Rhodes, 1998; Craddock et al, 1999; Wilkie et al, 2001; Wydra, 2001; Williams and Schreier, 2004; Carey et al, 2006; Kato and Beale, 2006; Kearney et al, 2006). Five of these studies investigated patients' perceptions of providing self care information utilising different formats such as videotapes (McDaniel and Rhodes, 1998; Carey et al, 2006), video games (Kato and Beale, 2006) and computers (Wilkie et al, 2001; Kearney et al, 2006), whilst several others, shown in Table 3.2, have used a randomised controlled trial design to assess the impact of self care information on a range of patient outcomes (Dodd,

1983; 1987; 1988; Walker, 1992; Hagopian, 1996; McDaniel and Rhodes, 1998; Craddock et al, 1999; Wydra, 2001; Williams and Schreier, 2004). Such outcomes have included improvements in patients' self care knowledge (Dodd, 1983; 1987; 1988; Walker, 1992; Hagopian, 1996), self care abilities (Wydra, 2001), level of involvement in self care (Dodd, 1983; 1987, 1988; Walker, 1992; Hagopian, 1996; Williams and Schreier, 2004) and reductions in symptom occurrence and distress (Walker, 1992; Hagopian, 1996; McDaniel and Rhodes, 1998; Williams and Schreier, 2004). However, some studies have found that the provision of self care information has not influenced the use, nor effectiveness, of patients' self care behaviours (Craddock et al, 1999) and has had little impact on the level of symptom severity and distress experienced by patients (Dodd, 1987; 1988; Craddock et al, 1999). The reasons behind these findings, however, appear not to have been investigated, justifying the need for future work to consider patients' experiences of self care to ascertain why and how patients undergoing treatment for cancer perform self care. Other studies have reported that information can help to alleviate feelings of helplessness, uncertainty and anxiety (Williams and Schreier, 2004) and help to prepare patients for the experience of treatment (McDaniel and Rhodes, 1998), however, some have reported no such associations (Dodd, 1987, 1988).

| Study/Country | Sample | Intervention | Instruments | Results |
|------------------------|--|---|--|---|
| Dodd (1983) USA | n=48 Patients receiving chemotherapy | - Random allocation to one of four groups; drug information only, side effect management information only, both the drug and side effect management information, or standard care (control group) | - Self Care Behaviour Questionnaire | - Patients in the side effect management information group demonstrated an increased participation in self care, ($F(1, 44) = 7.70, p < 0.01$) |
| Dodd (1987) USA | n= 60 Patients receiving radiotherapy | - Random allocation to either intervention or control groups: side effect management information (SEMI) (intervention); standard care (control) | - Self Care Behaviour Log (Dodd, 1984) - State Trait Anxiety Inventory (Spielberger et al, 1970) - Cancer Health Locus of Control scale (Dickson et al, 1985) | - Patients who received the SEMI demonstrated an increased participation in self care ($t(58) = 2.40, p = 0.02$) - Patients who received the SEMI demonstrated no significant change in average symptom severity (3.45 vs 3.26, $p = 0.34$) or distress (3.18 vs 3.0, $p = 0.38$) - Patients who received the SEMI demonstrated significant reduction in anxiety over time (35.9 pre intervention vs 30.4 post intervention, $p = 0.004$). - Anxiety and control were not significantly associated with self care (no value reported) |
| Dodd (1988) USA | n=60 Patients receiving chemotherapy | - Random allocation to either intervention or control groups: side effect management information (SEMI) (intervention); standard care (control group) | - Self Care Behaviour Log (Dodd, 1984) - State Trait Anxiety Inventory (Spielberger et al, 1970) - Multidimensional Health Locus of Control scale (Wallston et al, 1978) | - Patients who received the SEMI demonstrated an increased participation in preventative self care ($M = 203, SD 1.8$) than control group patients ($M = 0.87, SD 1.6$) ($p = 0.012$) - Patients who received the SEMI demonstrated no significant change in average symptom severity (2.98, $SD 0.99$ vs 3.28, $SD 0.68, p = 0.16$) or distress (2.18, $SD 1.1$ vs 2.95, $SD 0.97, p = 0.67$) - Patients who received the SEMI demonstrated significant reduction in anxiety over time (43.3 pre intervention vs 34.9 post intervention, $p = 0.001$) |
| Hagopian (1996) USA | n=75 Patients receiving radiation therapy | - Post-test control group design. Random allocation to intervention or control groups: audiotapes containing self care information (intervention) and standard care (control) | - Radiation side effects profile (RSEP) (Hagopian, 1990) - 23 item multiple choice knowledge test - Survey of satisfaction with audiotapes | - Increase in self care knowledge ($p = 0.0005$) - Increase in participation in self care ($p = 0.04$) - Increase in helpfulness of self care ($p = 0.01$) |

(Table continued on next page)

| Study/Country | Sample | Intervention | Instruments | Results |
|-----------------------------------|--|--|---|--|
| McDaniel & Rhodes (1998) USA | n=20 Patients receiving chemotherapy | - Random allocation to intervention or control groups: preparatory sensory information videotape (intervention) and standard care (control) | - Index of Nausea and Vomiting Form 2 (Rhodes et al, 1987) - Adapted Symptom Distress Scale Form 2 (Rhodes et al, 1984) | - Reduction in symptom occurrence and distress (values not reported) |
| Craddock et al (1999) USA | n= 48 Patients receiving chemotherapy | - Random allocation to intervention or control groups: oral and written self-care information (intervention); standard care (control). Both groups also received three telephone interviews | - Exercise of Self Care Agency Scale (Kearney and Fleischer, 1979) - Effectiveness of Self Care Questionnaire (modification of Nail Self Care Diary) (Nail et al, 1991) | - No increase in participation in self care (p=0.385) - No change in effectiveness of self care (p=0.314) - Significant association between self care agency and self care following treatment 2 (p=0.002) and treatment 4 (p=0.006) |
| Wydra (2001) USA | n=174 Patients with cancer | - Random allocation to intervention or control groups: computer based videodisc module containing self care information (intervention); conventional self care instruction + standard care (control) | - Wide Range Achievement Test 3 (WRAT 3) (Jastak and Wilkinson, 1984) - Pre and post item form to measure self care ability - 68-item checklist to identify the instructional content - 5-point Likert Scale to identify perceptions to the module - Follow up questionnaire 1 month after intervention to identify the self care practices of patients | - Increase in self care abilities (p=0.0001) |
| Williams & Schreier (2004) USA | n=70 Patients receiving chemotherapy | - Random allocation to intervention or control groups: audiotape containing information on side effects and self care (intervention) and standard care (control) | - Nail Self Care Diary (Nail et al, 1991) - State Trait Anxiety Instrument (STAI) (Spielberger et al, 1983) | - Increase in participation in self care - No significant change in mean severity of side effects - Reduction in anxiety (<i>values not reported</i>) |

Table 3.2: Selected randomised controlled trials of studies on informational interventions in patients undergoing treatment for cancer

3.6.2 Self Management Interventions

Kennedy and Rodgers (2001) acknowledge that promoting involvement in self care is not simply about the provision of self care information, but it also involves helping patients to translate their self care knowledge into practical skills that they can use, providing emotional support, and helping patients to build their confidence in relation to judging when self care is necessary and in evaluating the effectiveness of their self care behaviours. A number of interventions of this nature have been evaluated in patients with cancer (shown in Table 3.3) (Benor et al, 1998; Braden et al, 1998; Oliver et al, 2001; Wengstrom et al, 2001; Given et al, 2004; Miaskowski et al, 2004; Ream et al, 2006). Perhaps the most well known of these interventions is the American-based, Pro Self Programme, evaluated by Miaskowski et al (2004), where patients and nurses were encouraged to work together to identify self care goals and develop self care plans, where patients learned how to assess and track the changing nature of the effects of their cancer and its treatments, and where they were coached and supported in carrying out self care and evaluating the effectiveness of these.

A number of papers have described the programme (Larson et al, 1998; Dodd and Miaskowski, 2003; West et al, 2003), however, the most detailed account of its evaluation was recently conducted in the USA by Miaskowski et al (2004) and focussed on the management of cancer-related pain (The Pro Self Pain Control Programme). This evaluation was a randomised controlled trial and was conducted on a one to one basis with patients and their caregivers in their homes and also over the telephone during a six week period. The results revealed that patients (n=174) randomised to receive the intervention experienced significant reductions in pain intensity ($p < 0.0001$) and significantly more appropriate pain medication prescriptions (the percentage of patients with the most appropriate type of analgesic prescription increased significantly from 28.3% to 37.0%, $p = 0.08$) (Miaskowski et al, 2004). It is believed that these changes may have been attributed to the education, skills training and coaching provided in the Pro Self Programme, as these aspects may have helped

to promote greater changes in pain medication prescriptions, changes in analgesic intake and changes in the patients' perceptions of pain experience (Miaskowski et al, 2004).

Other interventions, described in Table 3.3, have comprised similar elements as the Pro Self Programme and have led to some useful findings. These have included, improvements in patients' self care knowledge (Benor et al, 1998; Braden et al, 1998), improvements in patients' level of involvement in self care (Braden et al, 1998; Ream et al, 2006), reductions in symptom severity and distress, and improvements in patients' psychological well-being (Benor et al, 1998; Braden et al, 1998; Oliver et al, 2001; Given et al, 2004; Ream et al, 2006). Wengstrom et al (2001), however, found no significant effects of their intervention on patients' coping abilities.

The interventions have been provided in a variety of settings including, groups (Braden et al, 1998), one to one (Benor et al, 1998; Oliver et al, 2001; Ream et al, 2006), by telephone (Braden et al, 1998; Given et al, 2004) and to patients together with their carers (Benor et al, 1998; Given et al, 2004). Many have also provided self care and emotional support tailored towards patients' needs (Oliver et al, 2001; Wengstrom et al, 2001; Given et al, 2004; Ream et al, 2006).

| Study/Country | Participants | Intervention | Instruments | Results |
|----------------------------------|---|--|--|---|
| Benor et al (1998) Israel | n=94 Patients with cancer receiving chemotherapy and radiotherapy | <ul style="list-style-type: none"> - Random allocation - Intervention – symptom assessment, patients are educated, advised, guided and supported in choosing self care strategies (10 sessions over 3 month period) - Control – standard care | <ul style="list-style-type: none"> - The Symptom Control Assessment Scale (SCAS) (Benor et al, 1998) | <ul style="list-style-type: none"> - Increased self care knowledge ($p<0.00$) - Increased perceived control over self care ($p<0.01$) - Reduced intensity of some physical and psychological symptoms ($p<0.00$) |
| Braden et al (1998) USA | n=193 Patients with breast cancer receiving different treatments (and family caregivers) | <ul style="list-style-type: none"> - Random allocation - Intervention(s) – (a) self help course (6 sessions over 6 wk period), (b) uncertainty management telephone intervention (weekly telephone calls over 6 wk period), or (c) combined self help course and uncertainty management intervention (attending same classes and receiving telephone calls as above over 6 wk period) - Control group – standard care | <ul style="list-style-type: none"> - Inventory of Adult Self Care Behaviours (Braden, 1993) - Self Care Inventory Wellness Promotion subscale (Pardine et al, 1983) - Inventory of Adult Role Behaviour (Braden, 1993) - Negative Affect Scale (Watson et al, 1988) - VAS to assess confidence in cancer knowledge | <ul style="list-style-type: none"> - Increase in self care, self help and confidence in cancer knowledge, and lower levels of negative affect state ($p=0.01$) |
| Oliver et al (2001) USA | n=67 Patients with cancer (treatments not specified) | <ul style="list-style-type: none"> - Random allocation - Intervention – tailored education session and coaching to identify treatment goals and communication methods with physicians (1 session during 2 week period) - Control – standard education session following outline of a pain education pamphlet | <ul style="list-style-type: none"> - Numerical scale (0-10) to assess average pain (Jensen et al, 1998; DeLoach et al, 1998) - Medical Outcomes Study Patient Assessment Questionnaire (Sherbourne, 1992) - American Pain Society Guidelines for the Treatment of Pain Patient Outcome questionnaire (American Pain Society Quality of Care Committee, 1995) - SF12 General Health Status Questionnaire (Ware et al, 1995) | <ul style="list-style-type: none"> - Reduction in average pain severity ($p=0.014$) - No significant impact on functional impairment, pain frequency, and pain related knowledge (<i>values not reported</i>) |
| Wengstrom et al (2001) Sweden | n=67 Patients with breast cancer undergoing radiation therapy | <ul style="list-style-type: none"> - Random allocation - Intervention – tailored education session, guidance in self care skills and psychological support - Control – standard care | <ul style="list-style-type: none"> - The Wheel Questionnaire (Shalit and Carlstedt, 1983) | <ul style="list-style-type: none"> - No significant effects of intervention on coping ability |

| Study/Country | Participants | Intervention | Instruments | Results |
|---|--|--|---|--|
| Given et al (2004) USA | n=237 Patients with cancer receiving chemotherapy (and family caregivers) | <ul style="list-style-type: none"> - Random allocation - Intervention – cognitive behavioural strategies, self care information, coaching in problem solving and communication, and counselling and emotional support (10 sessions over period of 20 weeks) - Control group – standard care | <ul style="list-style-type: none"> - Numerical scale (0-10) to assess presence and severity of symptoms | <ul style="list-style-type: none"> - Those who entered the intervention with higher symptom severity had a significantly lower severity at 20 weeks ($p<0.02$) |
| Miaskowski et al (2004) USA | n=174 Patients with cancer receiving a range of treatments | <ul style="list-style-type: none"> - Random allocation - Intervention – The Pro Self Programme – tailored education and coaching in self care strategies (3 visits and 3 telephone calls over period of 6 weeks) - Control – standard care | <ul style="list-style-type: none"> - Numerical scale to rate pain intensity (Ohnhaus & Adler, 1975; Downie et al, 1978) - Pain diary to record opioid analgesic intake, and changes to analgesic prescription | <ul style="list-style-type: none"> - Reduced pain intensity ($p<0.0001$) - Increased percentage of patients with an appropriate analgesic prescription from baseline ($p=0.08$) - Increased amount of analgesia taken (but not significant) |
| Ream et al (2006) (also Ream, 2002) UK | n=103 Patients with cancer receiving chemotherapy | <ul style="list-style-type: none"> - Random allocation - Intervention – assessment & monitoring of fatigue, education and coaching in self care strategies, and provision of emotional support (information pack given at start and 3 visits over period of 3 months) - Control – standard care | <ul style="list-style-type: none"> - Fatigue diary (containing four VASs to measure fatigue) (Ream et al, 2006) - Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983) - SF36 General Health Status Questionnaire (Ware et al, 1993) - COPE questionnaire (single VAS) (Carver et al, 1989) | <ul style="list-style-type: none"> - Reduced fatigue levels ($p<0.05$) (in particular, reduced associated distress $p<0.05$, and reduced impact on pastimes $p<0.05$) - Less anxiety ($p<0.05$) - Less depression ($p<0.05$) - More adaptive coping ($p<0.05$) |

Table 3.3: Selected randomised controlled trials of studies on supportive self care interventions in patients undergoing treatment for cancer

3.6.3 Critique of Intervention Studies

Despite the valuable findings of these studies in terms of their impact on patient outcomes, there are some notable methodological weaknesses within many of the intervention studies in Tables 3.2 and 3.3 which are considered in the following section. In particular, many of the studies in Tables 3.2 and 3.3 followed a blanket approach to promoting involvement in self care, rather than considering individual patients' preferences for information, and the influence of this on their subsequent involvement in self care. From the accounts of the interventions provided, the self care information and education provided in the majority of these seem to have been standardised (Dodd, 1983, 1987, 1988; Walker, 1992; Braden et al, 1998; McDaniel and Rhodes, 1998; Craddock et al, 1999; Wydra, 2001; Given et al, 2004; Williams and Schreier, 2004), rather than being tailored towards patients' preferences about the nature and format of information that they would have liked, its relevance and the time at which it was offered to them. Although it is difficult to determine from the accounts of the interventions, it could be questioned whether the information and education in these interventions was delivered to all patients regardless of their preferences or needs. Pellino et al (1998) claims that this is a common criticism of informational interventions, which are traditionally bound by a medical model and typically encompass the health professional as the expert who decides what, when and how much information the patient should receive. Only five of the interventions in Table 3.3 described offering self care information and education that was tailored and individualised to the preferences of patients (Benor et al, 1998; Oliver et al, 2001; Wengstrom et al, 2001; Miaskowski et al, 2004; Ream, 2002; Ream et al, 2006).

In all of the interventions discussed here, it is difficult to determine whether the individuality of patients, their perceptions and experiences and the factors that they perceived to influence their involvement in self care were considered. This kind of blanket approach has been found to be ineffective for promoting involvement in self care. In the recent evaluation of the pilot phase of *The Expert Patient Programme*, Kennedy et al,

(2005) identified that the current delivery and standardised content of the course was too rigid to respond to individuals' needs and acknowledged that the delivery of a generic, structured, 'one size fits all' approach in promoting patients involvement in self care was problematic since patients could not relate to it. Although, the variety of formats of information that was offered to patients in the informational interventions in Table 3.2 is encouraging, for example, written booklets (Craddock et al, 1999), audiotapes (Hagopian, 1996; Williams and Shreier, 2004), videotapes (McDaniel and Rhodes, 1998) and computers (Wydra, 2001), no studies were identified which have compared the efficacy between these approaches and patients' preferences on their optimum choice of format.

Cross comparison of the studies in Tables 3.2 and 3.3 is challenging since in many studies it was difficult to determine the extent to which the development of the intervention is guided by a theoretical or conceptual framework, as acknowledged in the discussion of Orem's Model of Self Care in section 3.2.4.1. There were examples of studies where authors referred to key theorists in the area of self care research, for example, Dodd (1987, 1988) who referred to the work of Orem and Levin, and McDaniel and Rhodes (1998) who referred to the work of Leventhal, yet it is unclear whether, and how, their interventions were derived from this work. Other studies clearly cited that their interventions were based on Orem's Self Care Model (Craddock et al, 1999; Wengstrom et al, 2001; Williams and Schreier, 2004), Learned Response to Chronic Illness and Uncertainty in Illness theories (Braden et al, 1998), Bandura's Social Cognitive Theory (Given et al, 2004) and Wittingham's Psychobiological Entropy Model (Ream et al, 2006). However, there were some studies which did not provide information on whether their intervention had been guided by a particular theory or conceptual framework (Walker, 1992; Benor et al, 1998; Wydra, 2001; Oliver et al, 2001; Miaskowski et al, 2004).

Cross comparison of the interventions is further complicated since each intervention consisted of different components and were delivered in different ways and for different

durations. The previous sections (sections 3.6.1 and 3.6.2) highlighted that the interventions in Tables 3.2 and 3.3 consisted of a variety of approaches including, written information and video tapes, and were delivered in group and individual settings, with or without carers. However, the content of many of the interventions also varied for example, some interventions contained approaches designed to coach patients how to communicate better with their physician (Oliver et al, 2001; Given et al, 2004), whilst others concentrated on teaching patients how to assess the nature of symptoms that they experienced (Benor et al, 1998; Ream et al, 2006). On the other hand, the Pro-Self Pain Control Programme consisted of a combination of approaches focussing on educating patients about the nature of cancer-related pain and its' assessment and management as well as coaching in how to communicate with their doctor about unrelieved pain and the need for changes to their pain medication prescriptions (Miaskowski et al, 2004). The different components which comprise such interventions make it difficult to tease out which elements help to produce changes in patients' self care behaviour and impact upon their physical and emotional wellbeing. Such weaknesses prompt future research to focus on qualitatively investigating patients' perceptions of such interventions to determine the elements that they perceive to be most helpful.

By way of an example of the value in qualitatively investigating patients' perceptions on the aspects of self management programmes that are welcomed by patients, Schumacher et al (2002) conducted a qualitative investigation of the nurse-patient interactions during the implementation of the Pro Self Pain Control Programme, evaluated quantitatively by Miaskowski et al (2004). In particular, the qualitative investigation revealed that patients particularly welcomed the self care teaching booklet and emphasised that interventions should focus on assessment and problem solving specific to patients' and coaching patients how to put self care management strategies into practice (Schumacher et al, 2002). Schumacher et al's (2002) findings highlight the importance of this approach however, few researchers have attempted to qualitatively explore patients' perceptions of self

management or, as identified earlier in the chapter, their perceptions on barriers and influences of their involvement in self care. Ream (2002) also noted the importance of a qualitative component to her quantitative study (also described in Ream et al, 2006) for highlighting the elements of the intervention that were most welcomed by patients. A qualitative component would also have been useful in studies which showed poor effects from their interventions for example, in Dodd's (1987, 1988) and Craddock et al's (1999) studies which had little impact on symptom severity and distress experienced by patients, and Wengstrom et al's (2001) study which found no effect of the intervention on patients; coping abilities, in order to determine possible explanations for these findings.

Another point worth noting in relation to the intervention studies in Tables 3.2 and 3.3 is the variability in the duration over which the interventions were delivered to patients. Many of the interventions were delivered to patients as a one off intervention (Dodd, 1983, 1987, 1988; Walker, 1992; Hagopian, 1996; McDaniel and Rhodes, 1998; Oliver et al, 2001; Wydra, 2001). However, other interventions were delivered on several occasions or over a specific period of time (Benor et al, 1998; Braden et al, 1998; Craddock et al, 1999; Given et al, 2004; Miaskowski et al, 2004; Williams and Schreier, 2004; Ream et al, 2006) with the effect of continuously reinforcing self care education. The durations of the delivery of these interventions however, have varied widely ranging from for example, a six-week period (Miaskowski et al, 2004) to three months in Benor et al's (1998) and Ream et al's (2006) interventions. It could be suggested that patients' involvement in self care may vary according to the length of time over which they are exposed to a self care intervention. It would seem reasonable to assume that the longer a person receives instruction and coaching in self care alongside emotional support, the greater their involvement in self care is likely to be. Hence, owing to the variability in the durations of the interventions in Tables 3.2 and 3.3 it is difficult to determine the optimal duration for a self care intervention.

A further aid to the development of such interventions in future research is to consider the reasons why patients have refused to participate in, or have subsequently withdrawn from such interventions. Some authors do report on these issues and found that the most common reasons included, 'patients were not interested' or 'did not feel they had a need for the intervention', 'were too overwhelmed by their disease and treatment', 'were too ill', or 'were too busy' (Braden et al, 1998; Oliver et al, 2001; Given et al, 2004; Miaskowski et al, 2004). These factors are important to understand since they influence patients' decisions to engage in a particular type of intervention (Ream et al, 2005) and may be useful for informing the design of different types of interventions in the future.

Although many of the intervention studies were strengthened in one respect by their experimental design and random allocation of patients (Dodd 1983, 1987, 1988; Benor et al, 1998; Braden et al, 1998; McDaniel and Rhodes, 1998; Craddock et al, 1999; Oliver et al, 2001; Wengstrom et al, 2001; Wydra, 2001; Given et al, 2004; Miaskowski et al, 2004; Williams and Schreier, 2004; Ream et al, 2006), some of the intervention studies in tables 3.2 and 3.3 included small samples sizes for example, n=48 (Dodd, 1983; Craddock et al, 1999), n=67 (Oliver et al, 2001), and n=70 (Williams and Schreier, 2004). Consequently, this led to even smaller numbers within the intervention and control arms and limited their generalisability. Furthermore, the representativeness of some study samples could be further questioned since few of these experimental studies (Dodd, 1987; Dodd, 1988; Benor et al, 1998; Braden et al, 1998; McDaniel and Rhodes, 1998; Craddock et al, 1999; Oliver et al, 2001; Wengstrom et al, 2001; Williams and Schreier, 2004) gave details on the use of a power calculation to determine an accurate sample size for their study and failed to offer a rationale for the absence of this.

The characteristics of the participants recruited to the studies are also worth considering. Some studies attempted to minimise the variability of clinical factors on patients' self care behaviours by recruiting a homogenous group of patients for example, patients with one

type of tumour (Braden et al, 1998; McDaniel and Rhodes, 1998; Craddock et al, 1999; Williams and Schreier, 2004). However, most studies incorporated samples of patients with different tumour types (Dodd, 1987; 1988; Benor et al, 1998; Oliver et al, 2001; Given et al, 2004; Miaskowski et al, 2004; Ream et al, 2006), patients with different stages of cancer (Dodd, 1987; Dodd, 1988; Braden et al, 1998; Craddock et al, 1999; Oliver et al, 2001; Given et al, 2004; Williams and Schreier, 2004) and patients undergoing different types of treatments (Benor et al, 1998; Braden et al, 1998; Oliver et al, 2001; Wydra, 2001; Miaskowski et al, 2004) thus, increasing the variability within the sample. In two studies it was unclear what tumour type the patients in the sample had been diagnosed with (Hagopian, 1996; Wydra, 2001). On the one hand, the recruitment of heterogeneous samples can improve the potential for generalising the study findings, however, the mix of different clinical factors such as tumour type, the stage of the tumour and treatment type may influence patients' self care needs and level of involvement in self-care. For example, tumour type and stage of the tumour determines the types and schedules of treatments that are offered to patients, the morbidity pattern, the long term effects and the methods of administration differ between different types of treatment which may influence patients' abilities to self care. Thus, it could be questioned whether the positive results found in many of these studies is a consequence of the intervention itself or merely a reflection of the effects of other clinical factors. Furthermore, Ream et al (2005) noted that patients' self care needs may differ depending upon their stage in the treatment journey. Thus, the use of heterogeneous samples makes it difficult to determine how patients' self care needs differ across the cancer and treatment journey and who benefits most from being involved in self care.

There are further concerns relating to the composition of the samples in many of the interventions in Tables 3.2 and 3.3 since many recruited samples predominantly comprising Caucasian and highly educated individuals (Braden et al, 1998; Craddock et al, 1999; Oliver et al, 2001; Wydra, 2001; Miaskowski et al, 2004; Williams and Schreier, 2004). It

is questionable, therefore, whether these studies adequately reflect the range of individuals who are affected by cancer, in terms of different cultures and different levels of education, and whether it was these characteristics that influenced the study findings. Ultimately, this makes it less feasible to generalise these findings to other groups of patients with cancer and those from other cultural and educational backgrounds. Furthermore, there has been little attention paid to those individuals living rurally. It could be suggested that individuals from cultures, who are commonly associated with delays in accessing medical services and those with lower education levels or living rurally, may have the greatest need for this type of supportive self-care intervention since healthcare services are perhaps more difficult to access or reach.

Concluding the effectiveness of the interventions in tables 3.2 and 3.3 is further hindered by the variability that exists in the outcomes chosen to evaluate the intervention and the instruments chosen to evaluate these outcomes. Studies have evaluated intervention effects in terms of knowledge (Hagopian, 1996; Benor et al, 1998; Braden et al, 1998; Oliver et al, 2001), level of involvement in self care (Dodd, 1983, 1987, 1988; Hagopian, 1996; Braden et al, 1998; Craddock et al, 1999; Williams and Schreier, 2004), changes in symptom severity and distress (Dodd, 1987, 1988; McDaniel and Rhodes, 1998; Oliver et al, 2001; Given et al, 2004; Miaskowski et al, 2004; Williams and Schreier, 2004; Ream et al, 2006) and level of anxiety or depression (Dodd, 1987, 1988; Williams and Schreier, 2004; Ream et al, 2006). Other outcomes have included, functional ability (Oliver et al, 2001), self care agency (Craddock et al, 1999) and perceived coping ability (Wengstrom et al, 2001; Ream et al, 2006). Only four studies evaluated intervention effects on patients' perceptions of control or confidence (Dodd, 1981, 1988; Benor et al, 1998; Braden et al, 1998). Therefore, although all studies focus on distinct outcomes, since these vary so widely there is a lack of a large and consistent evidence base to confirm the impact interventions designed to promote involvement in self care. Furthermore, none of these studies focussed on the

intervention effects in terms of their economic impact when compared with current standard practice.

The use of short term follow up periods for assessing outcomes (this was less than five months in all of the intervention studies in Tables 3.2 and 3.3) and the lack of the use of repeated measures and longitudinal designs, as well as a lack of longer term follow up cohort studies mean that little is known about whether these interventions produced changes, and indeed sustained changes, in patients' level of involvement in self care beyond the length of the intervention period. Perhaps this may have been because many of these interventions focussed on patients who were receiving a specific course of treatment for example, chemotherapy or radiotherapy, which may have been given over a fairly short period of time and which, therefore, did not allow for long term changes in patients' involvement in self care to be determined. Richardson et al (2005) identified, however, that researching the longer term impact of self care interventions is challenging since longer term follow up periods increase the risk of control group contamination in the absence of barriers to control group patients adopting the same self care strategies as the intervention group. Nonetheless, future research assessing longitudinal changes in self care over the duration of patients' treatment and beyond and establishing the long term impact of self care interventions would be useful for strengthening the evidence on self care and for informing and enriching the future development of interventions to promote involvement in self care.

As a final point, there are further inconsistencies relating to the impact of self care interventions because of the use of different instruments to measure intervention outcomes. Many of the studies in Tables 3.2 and 3.3 employed well validated instruments for example, the Nail Self Care Diary (Nail et al, 1991), the Multidimensional Locus of Control Scale (Wallston et al, 1978), the State Trait Anxiety Instrument (Spielberger et al, 1983), and the Hospital, Anxiety and Depression Scale (Zigmond and Snaith, 1983), however, others

employed instruments which were specifically developed for a study, often without providing the reader a rationale for doing so. Furthermore, the reliability and validity of these instruments are questionable since their use was not supported by reasonable information on their psychometric properties. Examples include, Dodd (1983), Benor et al (1998), Craddock et al (1999), Wydra (2001) and Given et al (2004) who developed their own versions of symptom assessment and self care questionnaires and who have not supported this with a reasonable rationale and information on psychometric testing. Of particular note, Wengstrom et al (2001) employed a questionnaire designed to measure perception in ability to cope with stress however, they reported that there had been no information on the psychometric properties of this tool reported within the literature, yet still chose to use this in their study with little explanation.

As a result of the weaknesses discussed here in relation to many intervention studies focussing on promoting the involvement of patients undergoing treatment for cancer in their self care, the evidence base on the conclusiveness of their impact, and indeed their sustained impact, on patient outcomes is inconclusive. In addition, this also makes it difficult to determine the most appropriate methods by which to promote the involvement of patients with cancer in self care. Only one self care intervention was conducted in the UK (Ream et al, 2006) questioning the relevance of the findings from other studies within a UK context.

3.7 Overall Summary of the Chapter

This chapter has highlighted the nature of self care and its theoretical underpinnings and has helped to emphasise its' relevance within the realm of current health policy, stimulating a growing interest in, and political support for, self care. Ultimately, there needs to be a greater understanding of health professionals' responses to, and perceptions of, such policies and the guarantee that a patient focus becomes embedded within health policy and is at the heart of future research on self care. A greater level of recognition of the individuality of patients and how their unique perceptions and experiences shape their

involvement in self care is valuable. This is important for encouraging a greater level of support for self care, for ensuring a greater level of collaboration between patients, carers and health professionals and for avoiding what could potentially be a reality in underpinning a patient-centred philosophy of care, from simply becoming policy rhetoric. Further work is needed to assess the impact of self care in order to support this stance. The current study aimed to address some of the gaps highlighted in this chapter by investigating the meanings that patients undergoing chemotherapy treatment for colorectal cancer ascribed to their self care, investigating their perceptions and experiences of being involved in self care during a six month course of treatment and whether their perceptions of control and self efficacy influenced their level of involvement in self care.

The following chapter considers the nature of perceived control and self efficacy and its' relationship to self care behaviour in patients with cancer.

Chapter 4 Perceived Control

4.1 Introduction

Perceived control and self efficacy are psychological constructs which reflect the extent to which an individual believes that they have a degree of control or influence over an event or behaviour (Walker, 2001), or confidence in their ability to perform a particular behaviour (Bandura, 1997). A wealth of research has highlighted that these constructs have been found to play an important role in predicting, and explaining, many areas of human functioning and behaviour. The following chapter considers the nature of perceived control, a central component of Leventhal's Self Regulation Model (Leventhal et al, 1984, 1997, 2001) which was used as the theoretical basis for the current study, and self efficacy and their role in individuals' responses to illness, and to self care in relation to patients receiving treatment for cancer. The chapter begins with a consideration of the difficulties in defining perceived control and its role in relation to patients' illness behaviour. The chapter then considers the role of self efficacy in relation to illness behaviour and its relationship with perceived control, before finally discussing the role of perceived control and self efficacy in relation to patients' involvement in self care.

4.2 Perceived Control

4.2.1 Defining Perceived Control

A number of health behaviour theories and models relate to the construct of perceived control, for example, the Theory of Planned Behaviour (Ajzen, 1991), Social Cognitive Theory (Bandura, 1997), Rotter's Social Learning Theory (Rotter, 1954, 1966), and Leventhal's Self Regulatory Model (Leventhal et al, 1984, 1997, 2001), however, it has been claimed that perceived control is not associated with one particular theory or model (Walker, 2001). Perhaps the reason for this lack of theoretical clarity lies in the heterogeneity and overlap that exists amongst the use of constructs to describe control - over 100 different conceptualisations of perceived control that have been identified in the literature (Skinner, 1996). Each of these conceptualisations appear to have their own

unique definitions yet they also seem to be interrelated and overlapping, and consistent with the predictive utility of perceived control (Thompson and Spacapan, 1991; Skinner, 1996). Some examples of these terms include, personal control, sense of control, locus of control, primary control and secondary control (Skinner, 1996), illusion of control, personal causation and personal agency (Wegner, 2002). Adding to the confusion, is another set of constructs which do not explicitly use the word 'control' yet seem to be closely related to the concept, for example helplessness, self efficacy, agency, capacity, mastery, self-determination, competence, causal attributions and outcome expectancy (Thompson and Spacapan, 1991; Skinner, 1996). Skinner (1996) points out that many of the terms referred to here appear to be different labels for the same construct, whilst other researchers use the same terms to refer to very different constructs.

The lack of clarity of control-related constructs and definitions creates a number of difficulties in this field of research, as Skinner (1996) and Wegner (2002) alluded to, and which still hold true today. The synonymous use of control-related terms has done little to facilitate theoretical coherence and clarity within this area of research, promote the accumulation of robust and consistent research findings and, pragmatically, to help researchers decide which constructs of control are most relevant to the outcomes of their research studies and how to measure these (Skinner, 1996; Wegner, 2002).

The distinction between the terms locus of control and perceived control is also difficult to identify. The term locus of control, was first developed by Rotter (1966) who refers to locus of control as being an individual's generalized expectations concerning where control over subsequent events resides. Locus of control is commonly distinguished as internal control, in which control over occurrences is attributed to the actions of the person themselves, and external control, in which occurrences are attributed to the actions of others, such as health professionals, and forces outwith their own actions such as fate or chance (Rotter, 1966). Internal control is associated with improvements in health-related

quality of life (Preau et al, 2005) amongst other outcomes, whilst external control has been found to be associated with lower preferences for involvement in decision making (Schneider et al, 2006), poorer psychosocial well being (White et al, 2006), deliberately poorer adherence to medication (Atkins and Fallowfield, 2006) and poorer attendance in cancer screening programmes (Gili et al, 2006). Internal and external control has often been measured in studies using the Multi-dimensional Health Locus of Control Scales (Wallston et al, 1978; 1994) (described in Chapter 6).

Confusingly, however, the term perceived control has also been used in studies where external and internal locus of control has been measured using these scales (Griffen and Chen, 2006). Link et al (2004) suggested that the distinction between locus of control and perceived control lies in the focus on internal and external influences within the construct of locus of control. Perceived control, on the other hand is believed to relate to perceptions of control over the course of the illness, its side effects and the effects of its treatments (Newsom et al, 1996), rather than being related to internal or external control. Perhaps the distinction in terminology used in individual studies also lies in the theoretical framework from which individual studies are based upon. Since Leventhal's Self Regulation Model was the theoretical framework within the current study, the definition of perceived control used to guide this study was that suggested by Newsom et al (1996) (as noted above).

4.2.2 Previous Research on Perceived Control

A high level of perceived control is believed to strengthen an individuals' intention to perform a specific behaviour, and increase their effort and perseverance (Ajzen, 2002). In relation to health benefits, a large body of research on perceived control in patients with a range of different illnesses has demonstrated that a greater sense of perceived control is associated with less physical symptoms from illness and improved physical functioning (Dracup et al, 2003; Jopson and Moss Morris, 2003; Doerfler et al, 2005; Norton et al, 2005; Calfee et al, 2006), positive psychological adjustment, including less anxiety and

depression (Taylor et al, 1991; Thompson et al, 1993; Newsom et al, 1996; Dracup et al, 2003; Jopson and Moss Morris, 2003) and is an important predictor, of recovery from illness (Johnston et al, 1999a, 1999b), adherence to medical treatment (Petrie et al, 1996; Griva et al, 2000; Horne and Weinman, 2002; Whitmarsh et al, 2003), and the use of positive health promoting and coping behaviours (Ziff et al, 1995; Cohen, 2002; Drossaert et al, 2003).

A recent American study by Dracup et al (2003) in 222 patients with heart failure, found that greater perceptions of control were associated with improvements in physical functioning and less emotional distress than patients with lower perceptions of control. Similarly, Jopson and Moss Morris (2003) found that a greater sense of perceived control over illness was associated with less physical fatigue, and less distress and depression in 168 patients with multiple sclerosis in New Zealand. However, both of these studies were cross sectional, therefore, the direction of causal relationships could not be established, and findings relating to patterns of change could not be identified. An American study by Doerfler et al (2005), in 52 patients at risk of post traumatic stress disorder (PTSD) following a myocardial infarction, found that lower perceptions of control were associated with more severe PTSD symptoms, and multiple hospitalisations. However, the small sample size (n=52) of this quantitative, cross-sectional study design limited the generalisability of this study's findings and did not allow causal relationships to be determined.

Studies in patients in the UK recovering from stroke (Johnston et al, 1999a, 1999b) have also found a predictive relationship between perceived control and improved recovery from disability as well as behavioural changes, however, one of these quantitative studies, in particular, recruited a small sample in relation to its study design (n=38, Johnston et al, 1999a) and, therefore, its generalisability was limited. A study in New Zealand by Petrie et al (1996) in 143 patients also found that non-attendance at a cardiac rehabilitation clinic for

patients during their recovery from MI, was associated with lower expectancies of abilities to cure or control their illness. Similar findings were identified by Whitmarsh et al (2003) amongst patients (n=93) attending a cardiac rehabilitation programme in the UK. Other studies have revealed an association between control and non-adherence to medication or medical advice in patients with diabetes (Griva et al, 2000), and asthma (Horne and Weinman, 2002). Some studies, for example, Ziff et al's (1995) study of employees (n=186) of a Massachusetts technology company found that greater perceptions of control were related to higher self-ratings of health, and were related to a greater level of health promoting behaviours, including, breast self examination, and exercise. This has been supported from the findings of large studies which have consistently reported an association between perceived control and participation in breast cancer screening (Drossaert et al, 2003) and breast self examination (Cohen, 2002).

4.2.3 Perceived Control in Patients with Cancer

Receiving a diagnosis of, and undergoing treatment for, cancer has been found to lower perceptions of personal control which in turn have been found to be associated with greater levels of physical impairment (Norton et al, 2005), feelings of illness uncertainty and psychological distress, and poorer adjustment (Thompson et al, 1993; Norton et al, 2005). On the other hand, higher perceptions of control have been found to be associated with better adjustment to cancer following diagnosis (Newsom et al, 1996).

In investigating the physical effects of perceived control, Norton et al (2005) identified that lower perceptions of control were related to greater levels of physical impairment, which in turn led to higher levels of psychological distress in patients (n=143) with ovarian cancer. Although the homogeneity in this study sample meant that the study findings were less likely to have been influenced by clinical factors such as cancer type, the cross sectional design, like many of the studies discussed in this chapter, made it impossible to establish

the direction of causal relationships, nor the pattern of changes in perceived control over time.

In relation to psychological distress and adjustment, a quantitative, cross sectional study in a heterogeneous sample of patients (n=71) with breast, colorectal, prostate, lung, cervical cancers and lymphoma in America, (Thompson et al, 1993), found that patients reported less depression and anxiety and better adjustment when they felt they had control over their emotions, physical symptoms and their physical recovery. However, the level of heterogeneity in terms of tumour type which existed in Thompson et al's (1993) study, made it difficult to determine how perceptions of control differed by cancer type. The importance of this was highlighted by Affleck et al (1987) who reported that the relationship between control and adjustment is moderated by health status and severity of disease, whilst Watson et al (1990) claimed that stage of disease may influence perceptions of control. As a result, the positive findings linking control and adjustment in a study of women (n=78) with breast cancer (Taylor et al, 1984), may have been because the women were reported as being asymptomatic and having a good prognosis. Hence, it is plausible to assume that different cancer types which consist of differing levels of severity or prognosis for patients may influence patients' perceptions of control.

Another criticism of Thompson et al's (1993) study was that it reported the median time since diagnosis for the patients in their sample as being 14 months hence, this study did little to illustrate how patients' perceptions of control in the period immediately following diagnosis influenced their emotional well being. It would have been interesting in Thompson et al's (1993) study to have been able to compare perceptions of control amongst patients immediately following diagnosis with those who were several months following diagnosis.

In one of the only longitudinal studies identified within control-related research, Newsom et al (1996) conducted an 8 month quantitative analysis of the association between perceptions of control and depressive symptoms in a heterogeneous sample of patients (n=161) with recurrent cancer. Newsom et al's (1996) study was interesting since not only was it longitudinal in design and was conducted in patients with advanced cancer, but it also measured the association of different constructs of control with depressive symptoms. Namely, these included, control over the factors which patients perceived were to blame for their diagnosis of cancer (self blame), control over the onset of cancer, control over the management of treatment related symptoms, control over the course of the cancer and control over life events. Their findings revealed that there were no significant associations between self blame, control over the onset of cancer and depressive symptoms but that greater perceptions of overall control and control over symptoms were associated with lower depression scores. Control over the course of the illness was only associated with depression at baseline but not longitudinally at the end of the 8 month study period. Although many of these findings are encouraging, the longitudinal analyses identified that control over the course of the illness and control over symptoms were not predictive of depression in the follow up assessment, therefore, questioning the causal links between these variables. Newsom et al (1996) pointed out that it may be that control over the course of illness and control over symptoms have more immediate effects on adjustment rather than longer term since symptoms and perceptions of prognosis are likely to vary over time. These findings should also be treated with caution owing to the high attrition rate within the sample (40% did not participate in the follow up assessment at 8 months) and the use of a heterogeneous sample made it difficult to determine how cancer type and stage of disease influenced patients' perceptions of control and thus, the association of control with depressive symptoms. Furthermore, patients who did not participate in the follow up had significantly poorer psychosocial and physical health, meaning that the findings from this study were limited in their generalisability to patients with poorer health.

It should be noted however, that despite the encouraging findings on the influence of perceived control on patients' physical and emotional well being referred to in this discussion, the majority of the studies referred to in sections 4.2.2. and 4.2.3 are quantitative, cross sectional studies meaning that perceptions of control were measured at one point in time and, therefore, patterns of change over time, the factors that influence maintenance of perceived control over time and causal relationships cannot be established. Furthermore, although these studies demonstrate that perceived control is considered to be a powerful predictor of human functioning and behaviour, few actually help to enrich our understanding of the rationales behind patients' perceptions of control, the particular ways in which patients gain a sense of control as well as the mechanisms by which perceived control has these effects. The following section considers the mechanisms by which perceived control may exert its influence on human functioning and behaviour.

4.2.4 How Perceived Control Works

The primary psychological mechanism by which perceived control influences outcomes is believed to be through its effects on action and action regulation (Skinner, 1995). Put simply, when people perceive that they have a high degree of control over their situation or the subsequent effects of their situation (for example, in managing the adverse effects of cancer treatment) they initiate action, exert more effort and persist in the face of failures and setbacks (Skinner, 1996). Furthermore, they are more interested, optimistic and focussed on problem solving (Skinner, 1996) and act in ways which help them to gain and sustain control (Skinner, 1995). The findings from a recent mixed method, cross sectional study by Link et al (2004) in patients (n=44) with cancer (types not stated, although breast and lung cancers accounted for the majority of the sample) support this view since they identified that patients who attempted to take control during their treatment were more likely to use proactive coping strategies. On the other hand, people who perceive that they have little or no control over their situation, tend to shy away from challenging situations and become

passive, avoid opportunities to regain or sustain control and can become distressed, pessimistic or fearful (Skinner, 1995; 1996).

Distinctions have also been made about perceptions of control over the course of the illness or the effects of the illness (Thompson et al, 1993). Indeed, this was demonstrated in Thompson et al's (1993) study in which a sense of control did not come from patients' perceptions that they could avoid the stressor (for example, undergoing chemotherapy treatment for cancer) but that they could develop a feeling of mastery over its consequences such as their emotional reactions or responses to physical symptoms. Newsom et al (1996) also supports this view claiming that perceptions of control can stem from various elements of the cancer experience including control over its cause and course as well as over the side effects of the disease and treatment. It has also been suggested that greater perceptions of control may also stem from having greater perceptions of control in other aspects of life, other than the stressor, in this case, a diagnosis of cancer (Taylor, 1983; Thompson et al, 1993). It is plausible that those who are able to maintain positive perceptions of control regardless of their influence over the stressor and who hold positive beliefs derived from the values and cognitions that they use to understand their world and live their life may be better adjusted following their diagnosis (Thompson et al, 1993).

Although it is widely accepted that higher perceived control is generally advantageous and adaptive, some reviews have concluded that people do not always want a greater level of control and that when they receive it, it can lead to negative reactions such as greater distress or impaired performance (Burger, 1989; Christnesen et al, 1991). Affleck et al (1987) also identified that higher perceived control amongst patients with rheumatoid arthritis was associated with poorer adjustment in patients who had more severe disease. The findings of a study of gay men (n=24) with AIDS (Reed et al, 1993) reinforced these earlier findings by identifying that beliefs about control by others over the course of their illness and over their medical care were negatively associated with adjustment and this

association was stronger in men who had reported poorer health. However, Thompson et al (1993) demonstrated that even in low control circumstances, for example, where one cannot necessarily influence the course of cancer, patients may be able to identify aspects of their situation that are under their influence. A cross sectional, mixed method study by Link et al (2004) in patients (n=44) with different types of cancer (with breast and lung cancers being the most common) identified that the decision to take control over the effects of their cancer did not seem to be related to stage of disease or perceived disease severity. The qualitative aspect of the study was particularly useful for highlighting the range of strategies that patients used in order to gain control over the effects of their cancer, however, the findings did not identify whether these perceptions varied by cancer type. This was one of the very few studies identified in this area of research that incorporated a qualitative component, however, further work is needed to build on these findings to determine what perceived control means to patients, how they attempt to gain control and how these change over time, and how their perceptions of control are influenced by severity or type of disease.

Vicarious control by others, for example health professionals, has also been suggested as having an important influence over patients' adjustment (Taylor et al, 1984; Reed et al, 1993). In a qualitative study of women (n=78) with breast cancer, Taylor et al (1984) found that 68% of the sample believed that there were others who could exert control over their cancer, namely physicians and other health care professionals. Furthermore they identified that this was positively related to their overall adjustment (Taylor et al, 1984) however, these findings were not confirmed by Reed et al's (1993) later quantitative study in 24 men with AIDS. The diverging findings however, may have been influenced by the size of the sample, the difference in gender between the studies, the design of the study or the nature of the disease being studied. Taylor et al (1991) suggests that since breast cancer is potentially curable through contact with medical professionals and medical treatment, vicarious control can be adaptive for those patients in comparison with other disease groups. Furthermore, in an earlier study, Taylor et al (1984) commented that the patients in

their sample were asymptomatic and had a good prognosis at the time of the interview which may have affected their findings. In addition to this, the study did not attempt to longitudinally explore whether these perceptions changed over time. Nonetheless, this study was valuable in relation to the current research study because of its qualitative design and, therefore, its ability to demonstrate the ways in which people gain control and also highlights the importance of the role that health professionals may play in contributing to patients' perceptions of control and their overall adjustment.

In addition to these mechanisms of perceived control, other suggestions on the mechanisms of perceived control relate back to the earlier discussion about the lack of clarity of control and control-related constructs. One mechanism in particular refers to a closely similar construct, namely self efficacy, which has frequently been associated with perceived control (Ajzen, 1991; Thompson and Spacapan, 1991; Thompson and Collins, 1995; Armitage and Conner, 1999a, 1999b; Ajzen, 2002). This construct is discussed in greater detail in the following section.

4.3 Self Efficacy

Self efficacy relates to 'the belief in one's capability to organise and execute the courses of action required to manage prospective situations (Bandura, 1997, p2). Therefore, rather than purely a measure of ability, self-efficacy relates to a measure of a person's belief or confidence in their ability to perform a particular ability (Bandura, 1997). From this definition it is apparent that the constructs of self-efficacy and perceived control, although distinct, are in effect very similar.

Like perceived control, a significant body of empirical research has demonstrated that self-efficacy has increasingly assumed a central role in predicting health related behaviours such as smoking cessation (Schnoll et al, 2004; 2005), participation in exercise and physical activity (Sallis et al, 1989; DuCharme and Brawley, 1995) and participation in cancer

screening programmes (Friedman et al, 1993; Mishra et al, 1998; Kremers et al, 2000; Jirojwong and MacLennan, 2003; Ford et al, 2004). In general, this research indicates that stronger or higher self-efficacy beliefs are beneficial, therapeutic and associated with the initiation and maintenance of positive health behaviour changes and also the effort and perseverance endured by the individual in performing that behaviour (Bandura, 1997). On the other hand, weaker self-efficacy beliefs are associated with poorer outcomes and negative behaviours.

Further research has demonstrated that self-efficacy is also an important predictor of successful adjustment to (Hirai et al, 2002) and recovery and rehabilitation from, illness (Gortner and Jenkins, 1990; Carroll, 1995; Robinson Smith and Allen, 2002), adherence to medication (Brus et al, 1999; Kobau and DiIorio, 2003) and is predictive of individuals' abilities to cope with and manage symptoms such as pain (Keefe et al, 1997; Lefebvre et al, 1999; Lorig et al, 1999; Edwards et al, 2001). Such findings allude to the central role of self-efficacy in relation to individuals' self care and self-management behaviour during, and following, illness. The role of self-efficacy, and perceived control, in influencing patients' self care behaviour is discussed later in this chapter however, the following section considers the evidence on the effects of self efficacy in patients with cancer.

4.3.1 Self Efficacy in Patients with Cancer

Several recent studies have addressed the role of self-efficacy in patients with cancer, highlighting that stronger self efficacy beliefs are associated with better adjustment to their cancer diagnosis and improved quality of life (Cunningham et al, 1991; Beckham and Burker, 1997; Northouse et al, 2002; Manne et al, 2006), decreased physical and psychological symptoms (Porter et al, 2002; Campbell et al, 2004; Manne et al, 2006) and less psychological distress (Beckham and Burker, 1997; Hirai et al, 2002). In one cross sectional study of a heterogeneous sample of male (n=42) patients with cancer (including lung, myeloma, leukaemia, lymphoma or colon cancer), self-efficacy was found to be a

significant predictor of adjustment and lowered levels of depression (Beckham and Burker, 1997) whilst a longitudinal 3 month intervention study by Cunningham et al (1991), in a heterogeneous sample of patients with cancer (n=273) (types not stated), reported it to be a significant predictor of quality of life. However, the heterogeneity in both of these samples makes it difficult to determine whether perceptions of self efficacy vary by cancer type. The sample in Cunningham et al's (1991) study comprised mostly females and individuals who were well educated hence, it is also not possible to confirm whether there is an interaction between gender and education level, and self efficacy. Furthermore, in Cunningham et al's (1991) study it may have been the intervention of a psycho-educational programme (comprising a seven weekly, 2 hour educational session) that increased patients' perceptions of self efficacy and led to improvements in their quality of life, however, the correlative nature of the study cannot confirm this nor that the improvements in quality of life were not simply due to the emotional benefits of the intervention. The cross sectional nature of Beckham and Burker's (1997) study also means that causal relationships and the pattern of changes in patients' self efficacy over time cannot be determined.

Few longitudinal studies on self efficacy in patients with cancer have been conducted to determine whether self efficacy predicts adjustment to cancer in the longer term. Koopman et al (2002) investigated the association between self efficacy to manage emotions and distress over a six month period in patients (n=117) with breast cancer. Their findings identified that self efficacy at baseline did not predict distress at the follow up assessment six months later. However, their study was focussed on emotional self efficacy, as opposed to other aspects of self efficacy which may have changed over time instead and may have more likely predicted distress in the longer term. More recently, Manne et al (2006) conducted a longitudinal, quantitative study to investigate changes in cancer-specific self efficacy and their associations with psychological and functional outcomes over a twelve month period among women (n=95) with breast cancer, shortly after surgery and one year later. Using repeated analysis of variance, the authors found that self efficacy remained

fairly stable over time with only two domains, activity management and self satisfaction, showing an increase during the study period. The analysis also revealed that there were many aspects of self efficacy that were related to outcomes, for example, higher affective management self efficacy was associated with higher self esteem at 1 year following surgery whilst higher communication self efficacy was associated with less functional impairment.

These findings are interesting and reinforce the importance of longitudinal investigations in assessing changes and associations over time in patients with cancer. However, Manne et al (2006) report that some of the patients who participated in their study had completed treatment by the time of the second assessment and hence their responses to the questions about self efficacy may have been based on different experiences. Furthermore, both Koopman et al's (2002) and Manne et al's (2006) findings may have been influenced by the fact that patients were newly diagnosed and had a fairly good prognosis and had no evidence of metastatic disease at the second time point which may have influenced patients' perceptions of self efficacy. However, these studies did incorporate homogenous samples of women with breast cancer which was useful for excluding the possibility that patients' perceptions of self efficacy differed by cancer type.

In relation to physical and emotional well being, Porter et al (2002) examined the degree of congruence in perceptions of the patients' self efficacy towards managing their cancer-related symptoms in patients (n=30) with lung cancer and their family caregivers and revealed that patients with high levels of self efficacy experienced fewer cancer-related symptoms. Although potentially valuable, these findings are limited in light of the cross sectional design of the study, the small sample size for a quantitative study in which the purpose would have been to generalise the results as much as possible and the use of self efficacy measure designed for use in patients with arthritis, rather than for use in patients with cancer. Hence, it is not known to what extent this measure has been tested in and is

appropriate for use in patients with cancer. Nonetheless, these findings have been supported by a similar quantitative study conducted in African American patients (n=40) with prostate cancer and their partners (Campbell et al, 2004) which identified that patients with high levels of self efficacy in relation to symptom control, reported better quality of life, better functioning and better mental health. However, again the cross sectional nature of this study limits these findings since, for example, it cannot be confirmed that self efficacy causes improvements in quality of life, and patterns of change in patients' self efficacy over time cannot be determined. Furthermore, the study may have lacked power to detect associations in this quantitative study between variables because of its small sample size. The authors comment that there was a high refusal rate for the study but provide no further information on this which may have helped to inform future research. Finally, the average time since diagnosis in the sample was 17.9 months and hence, this study fails to provide information about patients' perceptions of self efficacy and its effects in the period immediately following diagnosis, which would have provided an interesting comparison.

Despite the limitations of these studies referred to here collectively the findings from the studies reviewed provide information on the potential effects of self efficacy on physical and emotional well being in a diverse range of patients with different types of cancer. Furthermore, similar findings have been identified in studies in patients with other disease types such as, arthritis, in relation to improved symptom experiences and adjustment in patients with higher perceptions of self efficacy (Keefe et al, 1997; Lefebvre et al, 1999). Further work would be useful, however, to determine the factors that influence patients' perceptions of self efficacy and the ways in which perceptions of self efficacy change over time. The following section considers the mechanisms by which self efficacy is believed to influence human behaviour.

4.3.2 How Self Efficacy Works

According to self-efficacy theory, behaviour change and maintenance are a function of beliefs about the outcomes that will result and the expectations about one's ability to perform the behaviour (Strecher et al, 1986). Bandura (1997) maintains that such beliefs of self efficacy can have diverse effects, not only influencing the behaviour that an individual chooses to perform, but how much effort they will exert, how long they will persevere in the face of challenges in doing so and how they feel during the whole process. In general, those with high self-efficacy, like those with greater perceptions of control, are more likely to approach new challenges as tasks to be mastered rather than avoided (Bandura, 1997). They are more likely to set challenging tasks and maintain a high level of commitment to them, produce personal accomplishments and suffer less stress and depression (Bandura, 1997). In contrast, people with low self-efficacy, like those with low perceptions of control, are more likely to doubt their capabilities, viewing challenges as threats to be avoided rather than overcome, and have low aspirations and a weak commitment to the behaviours they choose to perform (Bandura, 1997). Such individuals are also slow to recover their sense of self-efficacy from failures or setbacks, quickly lose faith in their capabilities and are more vulnerable to the effects of stress, anxiety, and depression (Strecher et al, 1986; Bandura, 1997). It is important to note that an individual's self-efficacy beliefs may vary and change over time and in different situations (Fleury, 1992) and is, therefore, thought to be neither a trait nor a generalised response (Clark and Dodge, 1999).

These discussions highlight that there are apparent similarities between the constructs of perceived control and self efficacy, and the ways in which both work to influence patients' behaviours. The following discussion considers the relationship between the two constructs.

4.4 The Tension Between Perceived Control and Self Efficacy

Although some studies would claim that perceived control and self-efficacy are distinct constructs (Terry and O’Leary, 1995; Sparks et al, 1997; Manstead and Eekelen, 1998; Armitage and Conner, 1999a, 1999b), self-efficacy has, time and again, been linked to control and perceived control by a number of authors (Strecher et al, 1986; Ajzen, 1991; Thompson and Spacapan, 1991; Thompson and Collins, 1995; Skinner, 1996; Griva et al, 2000; Ajzen, 2002). Griva et al (2000) even found that control and self efficacy were highly correlated in a study of adherence in patients (n=64) with diabetes.

Theoretically, the two constructs appear to overlap and share similarities. Some authors consider self-efficacy to be fundamental to the achievement of perceived control (Bandura, 1977; Thompson and Collins, 1995; Walker, 2001; Ajzen, 2002), and have acknowledged that perceived control is compatible with social-cognitive theory (Johnston et al, 2004), from which self-efficacy is derived. In accordance with this, both constructs focus on the concept of ‘mastery’. However, as illustrated in Figure 4.1, Bandura (1997) identified that even if individuals believe that outcomes can be influenced by particular behaviours (perceived control), they will not attempt to exert control, unless they also believe that they themselves are confident in performing those behaviours (self efficacy) and of producing favourable outcomes as a result of these behaviours (outcome expectancies). This suggests that in making a decision about performing a particular behaviour, individuals hold both perceptions of control and self efficacy.

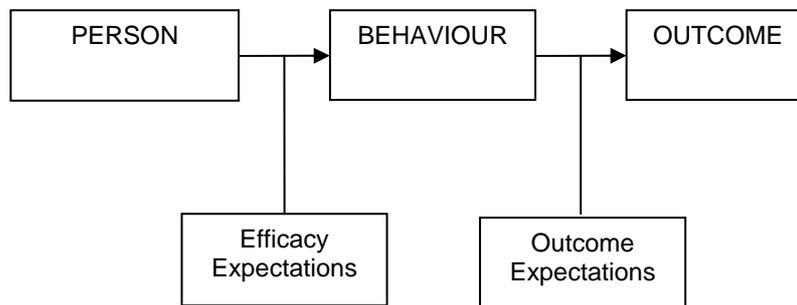


Figure 4.1: Diagram of efficacy and outcome expectations (Bandura, 1977)

Not only do both constructs share closely related definitions, both are said to be situation-specific, meaning that an individual's beliefs about perceived control and self-efficacy vary depending upon the situation of the individual and the behaviour to be performed (Ajzen, 2002). Furthermore, both constructs not only affect an individual's decision to initiate a particular behaviour but also an individual's effort and perseverance toward that particular behaviour (Bandura, 1997; Ajzen, 2002).

These similarities have prompted researchers to explore the factor structure of measures of perceived control and self-efficacy to identify their relationship (Terry and O'Leary, 1995; Sparks et al, 1997; Manstead and Eekelen, 1998; Armitage and Conner, 1999a, 1999b; Ajzen, 2002). Perceived control and self-efficacy were identified as two separate components in several of these studies (Terry and O'Leary, 1995; Sparks et al, 1997; Manstead and Eekelen, 1998; Armitage and Conner, 1999a, 1999b), however, Ajzen (2002) comments that these studies failed to examine the convergence between the two constructs, calling for further work in this area. Further questions remain about the relationship between the two constructs since the factor analysis studies discussed here, failed to be consistent about the items that were loaded onto factors labelled self-efficacy and those

labelled perceived control with the proposed definitions of self efficacy and perceived control (Ajzen, 2002).

In the current study, which considers both patients' perceptions of control and self efficacy in relation to self care behaviour, the quantitative data were considered to be particularly useful for identifying the associations between these constructs and how patients distinguish between them. These findings have been reported in Chapters 10. Having discussed both the constructs of perceived control and self efficacy, the ways in which these relate to each other, and the ways in which they influence patients' illness-related behaviours, the following section considers how patients' perceptions of control and self efficacy have been found to influence patients' involvement in self care, before narrowing to consider this amongst patients with cancer.

4.5 Perceived Control, Self Efficacy and Self Care

This chapter has so far highlighted that an overwhelming body of research has supported the positive effects of perceived control and self-efficacy on human behaviour and functioning. Studies have generally identified that stronger perceptions of control and self-efficacy are beneficial in promoting successful recovery and rehabilitation from illness (Johnston et al, 1999a), improvements in quality of life and physical and psychological functioning (Taylor et al, 1984, 1991; Thompson et al, 1993; Newcom et al, 1996; Dracup et al, 2003; Jopson and Moss Morris et al, 2003; Doerfler et al, 2005; Norton et al, 2005;) and helpful in encouraging individuals to follow medical advice or treatment (Petrie et al, 1996; Griva et al, 2000; Horne and Weinman, 2002; Whitmarsh et al, 2003). It would be plausible, therefore, to assume that such findings may hold implications for patients' self care and self-management behaviour. Thus, this has led some researchers, linking the constructs of perceived control and self efficacy with self care and self management behaviour, to suggest that individuals with stronger perceptions of control and self-efficacy are more likely to believe that they can influence or control the effects of their illness and

its treatments (perceived control) and that they are more confident in their abilities to manage these effects (self efficacy) and hence, may engage in more self care (Taylor et al, 1983; Lev, 1997; Bandura, 1998; Urquhart Law et al, 2000; Skinner and Hamson, 2001; Henderson and Donatelle, 2003; Sol et al, 2006).

In relation to perceptions of self efficacy, there is a large body of evidence which has revealed that patients with stronger self-efficacy beliefs are more likely to initiate and continue to maintain self-care behaviour in managing the side effects caused by their illness or treatment and have a better quality of life than those with low levels of self-efficacy. Such studies have focussed on a diverse range of patient groups, including, patients with coronary heart disease (Clark and Dodge, 1999), end stage renal disease (ESRD) (Tsay and Hung, 2004), arthritis and other chronic diseases (Lorig et al, 1993; Taal et al, 1996; Lorig et al, 1999; Barlow et al, 2000; Lorig et al, 2001, 2003; Wright et al, 2003; Lorig et al, 2005), systemic lupus erythematosus (SLE) (Sohng, 2003) and patients recovering from coronary artery bypass graft surgery (Carroll, 1995).

Most notably, the Arthritis, and Chronic Disease Self Management Programmes, developed by Lorig et al (1993, 1999, 2001, 2005), are interventions which aim to develop and encourage patients' participation in their self management through a self efficacy approach. Collectively, trials of these programmes have shown improvements in knowledge and symptom management, health distress, and have strengthened participants' self efficacy beliefs. Trials of the intervention have been conducted in numerous countries with a large and diverse sample of participants (Lorig et al, 1993, 1999; Barlow et al, 2000; Lorig et al, 2001; Lorig et al, 2003; Wright et al, 2003; Farrell et al, 2004; Griffiths et al, 2005; Lorig et al, 2005), highlighting its' relevance to a range of patient groups with diverse cultural characteristics.

Fewer studies, however, have investigated the role of perceived control in influencing patients' self care behaviour. Perhaps this reflects the earlier discussion on the difficulties in defining control-related terms and the fact that, in many instances, these terms are used interchangeably. One study conducted in the UK, in adolescents with diabetes (n=54), reported on the 1-year follow up data from a prospective study designed to examine the predictive utility of personal models of diabetes in relation to self care behaviour and wellbeing (Skinner and Hampson, 2001). This study identified that greater perceptions of control over treatment effectiveness were associated with greater dietary self care practices, and hence improved glycaemic control (Skinner and Hampson, 2001). Although, it should be noted that the sample were predominantly white, middle class individuals and, therefore, the lack of diversity within the sample limits the relevance of these findings to diverse populations. Furthermore, the cross sectional nature of this study did not allow patterns of change in perceptions of control and the ways in which this influenced self care behaviour to be explored. A further UK study in patients with diabetes (n=30) found no association between perceived control and self management behaviour, however, the cross sectional nature and sample size involved in this purely quantitative study leaves this argument open to question (Urquhart Law et al, 2002). Furthermore, the patients involved in Urquhart Law et al's (2002) study were adolescents who may have been generally less inclined to participate in their own self care.

More recently, Calfee et al (2006) identified no association between perceived control and preventative or self care in a prospective cohort study of patients (n=865) hospitalised for asthma in America. It should be noted, however, that patients' use of self management strategies may have been influenced by their perceptions of asthma control meaning, for example, that those patients who perceived their asthma to be well controlled may not have carried out a great deal of self care yet this was not measured in the study. Furthermore, the study is limited to those patients who were hospitalised for asthma and hence, this may reflect their beliefs towards self care.

4.5.1 Influence on Self Care in Patients with Cancer

In spite of the wealth of evidence on the role of self efficacy in the many different disease types mentioned above, only a small body of work has specifically investigated perceptions of self-efficacy (Lev and Owen, 1996; Lev et al, 1999; Lev et al, 2001) and control (Taylor et al, 1983; Benor et al, 1998; Henderson and Donatelle, 2003) and their influence on self care in patients with cancer.

In relation to perceptions of self efficacy, Lev and Owen (1996) examined the relationship between patients' perceptions of self efficacy to carry out self care and their quality of life and psychological symptoms in patients receiving chemotherapy (n=161) for cancer (cancer types not stated). Patients completed quantitative measures on one occasion during their treatment although it is not stated at which point during their treatment this was. The study findings revealed that greater perceptions of self efficacy to carry out self care, which the authors termed 'self care self efficacy', were positively associated with quality of life and negatively related to psychological distress, mood and symptom distress. However, these findings are limited since a description of the types of cancer investigated and the point during treatment at which patients were assessed is missing in this account. Furthermore, this study seemed to assume that greater perceptions of self efficacy to carry out self care (self care self efficacy) led to greater involvement in self care by patients, which may have brought about the improvements seen in quality of life and psychological symptoms. However, the authors failed to investigate whether there were any actual changes in patients' level of involvement in their self care.

In a longitudinal study investigating how self care self efficacy influences quality of life over time, Lev et al (1999) obtained complete data from 124 patients with cancer (including breast and lung cancer) across three time points during an 8 month period. The findings revealed that both self care self efficacy and quality of life significantly decreased over time. These findings, although being amongst the first known to investigate changes in

patients' perceptions of self efficacy over time (Lev et al, 1999), should be treated with caution since patients with differing types and stages of cancer (some reported metastatic disease compared to others who did not) were recruited and this may have influenced perceptions of self efficacy. Although, the relationship between perceptions of control and adjustment has been found to be moderated by severity of disease (Affleck et al, 1987), it is not known to what extent such factors influence patients' perceptions of self efficacy. There was also a high drop out rate from baseline to the completion of the eight month study (n=183), however, the authors do not attempt to explain this. Furthermore, although the study assesses patterns of change, it is not known at which points in the patients' treatment that these assessments occur and whether all patients were assessed at the same time points. Furthermore, it is unknown whether changes in self care self efficacy over time influenced actual changes in patients' level of involvement in self care.

Most recently, Lev et al (2001), conducted a quasi-experimental study to evaluate the effects of a nurse administered self efficacy intervention on patients' (n=56) perceptions of self care self efficacy and quality of life at the beginning of patients' chemotherapy treatment for breast cancer, and then again at four and eight months later. The researchers' initial hypotheses were supported with the experimental group demonstrating higher self care self efficacy scores and improvements in quality of life at four and eight months after beginning chemotherapy treatment, however it is important to note that complete data was received for only 18 patients, meaning that there was a large drop out from the initial baseline measurement, which may have influenced the reliability of the findings. Furthermore, although the authors concluded that efficacy enhancing interventions, such as the one tested in this study, may provide patients with the means to participate in self care (Lev et al, 2001), like in their earlier studies, the researchers failed to evaluate the effects of patients' perceptions of their self care self efficacy on their level of involvement in self care.

In relation to perceptions of control, a report on qualitative work conducted over a two year period with patients with breast cancer (n=78) and many of their family members (numbers not stated), was published by Taylor (1983). She commented that the individuals involved had received different prognoses and had achieved differing levels of quality of life following their illness, yet consistently the themes arising in the research related to attempts at mastery and self enhancement (Taylor, 1983), identifying that patients perceived themselves to have reasonable levels of control and a desire to take control. In particular, Taylor (1983) reports in her account that higher perceptions of control were most often associated with positive health-related behaviours believed to control the cancer, such as carrying out self care, dietary changes, meditation and imagery. Since this work has not reported on individual studies, however, it is not possible to comment on the quality of this work.

Two early quantitatively designed intervention studies, conducted in patients undergoing chemotherapy (n=48) (Dodd, 1987) and patients undergoing radiotherapy (n=60) (Dodd, 1988), focussed on the influence of the provision of structured side effect information on patients' involvement in self care and perceptions of control. The findings revealed that although the patients in both studies carried out a greater degree of self-care, perceptions of control were not significantly associated with involvement in self care in either study. However, perceptions of control were measured once rather than at several points in a longitudinal fashion and, therefore, did not reflect potential changes in perceptions of control as patients progress through their treatment. Furthermore, the sample sizes in both studies can be considered small for a quantitative study whilst Dodd (1987; 1988) acknowledges that neither study may have been sufficiently powered to detect minor changes. This is difficult to determine since details of whether any power calculations were carried out have not been provided.

An intervention study by Benor et al (1998) in a heterogeneous sample of patients (n=94) with cancer (including breast, colon, genital, prostate cancers and lymphoma), designed to promote their involvement in self care, found that an intervention consisting of ten structured home visits in which a nurse assessed patients' symptoms and intended to guide them in their choice of effective self care strategies, had also helped to increase patients' perceptions of control. However, it is not known to what extent patients' perceptions of control in this study had led to a change in patients' involvement in self care. Furthermore, perceptions of control over side effects were measured using an instrument developed for the study, which questions the reliability and validity of the instrument. Furthermore, perceptions of control seemed to be assessed once before the intervention and then following the intervention, rather than at multiple times during the intervention in a longitudinal design. Hence it is not known whether these perceptions changed at all during the actual intervention. This would have been particularly useful since Benor et al (1998) noted that all participants had high perceptions of control over side effects at the beginning of the study and thus, the findings may have been influenced by a ceiling effect (where perceptions of control were unlikely to increase beyond those reported at the beginning of the study), rather than the effects of the intervention itself.

In a quantitative study in patients (n=551) with breast cancer in America, Henderson and Donatelle (2003) investigated the relationship between perceived control and the use of complementary therapies, and found that perceived control over the course of their cancer predicted use of complementary therapies, including both physical and psychological therapies. Although encouraging, the cross-sectional design does not allow causal relationships to be established. Furthermore, the authors comment that no data was available for the stage and treatment type of the women who participated in the study, therefore, it is not known to what extent these factors may have influenced the women's perceptions of control and subsequent use of therapies.

4.6 Overall Summary of the Chapter

This chapter has highlighted that perceptions of control and self efficacy are believed to play an important role in influencing physical and psychological well being, adjustment and quality of life and adjustment amongst patients with cancer. Chapter 3 highlighted that enhancing patients' perceptions of control and self efficacy are believed to be important strategies for encouraging involvement in self care (Bulsara et al, 2004; Coon and Coleman, 2004; Kralik et al, 2004), and findings from studies in patients with other disease types appear to confirm this (Taal et al, 1996; Lorig et al, 1993, 1999; Barlow et al, 2000; Lorig et al, 2001; Lorig et al, 2003; Wright et al, 2003; Lorig et al, 2005). However, this has been investigated to a lesser extent amongst patients with cancer.

The findings from much of the existing research in this area are limited owing to the use of cross sectional designs which have failed to identify causal relationships and whether patients' perceptions of control and self efficacy change over time. Particularly relevant to the current study, research, including those rare longitudinal investigations which have been conducted, has notably failed to investigate how patients' perceptions of control and self efficacy relate to their involvement in self care during treatment for cancer. Furthermore, since most studies have been purely quantitative in nature, there is no evidence to identify the rationales behind patients' perceptions of control, the ways in which patients gain control during their treatment and the factors that influence their perceptions of self efficacy, and how these influence their involvement in self care. Relevant to the current study, few studies have assessed perceptions of control and self efficacy in newly diagnosed patients, and based on the sample composition of most studies it would seem that few have focussed on patients with colorectal cancer.

Specifically, in this current study, the researcher proposed to investigate the relationship of perceived control, self efficacy and self care behaviour in patients receiving chemotherapy treatment for colorectal cancer using a mixed method approach and longitudinal design.

This involved the use of structured questionnaires and a self care diary to quantitatively measure changes in patients' perceptions of their control, self efficacy and involvement in self care, and semi-structured interviews to identify patient's perceptions on their involvement in self care at the beginning and end of their chemotherapy treatment and how their perceptions of control and self efficacy influence their involvement. The rationale for using a patient focussed, mixed method, longitudinal approach is considered in greater detail in the following chapter.

Chapter 5 Patient Focussed Approach

5.1 Introduction

Chapters 2 and 3 highlighted the importance of involving people with cancer in self-care as a result of the growing use in outpatient and home based chemotherapy treatments, and because of the growing trend towards a greater political focus on self-care within the UK for all patients, irrespective of the nature of their long-term illness. Despite the complexities in defining self care, the earlier discussion around the theoretical and conceptual background to self care in Chapter 3 highlighted self care as an individualised and patient centred approach. However, as the subsequent discussions revealed there has been little focus within the UK policy and research literature on the individuality of patients and the meanings that they, particularly patients with cancer, attach to self-care and the implications that these have in relation to how they perceive their involvement in self care. It is also notable that there has been little consideration of the factors that influence patients' involvement in self-care, whether their patterns of involvement change over time, and the ways in which *they* perceive that they can be supported to engage in their self-care.

The purpose of the current research study was to explore perceptions and experiences of being involved in self care and perceptions of control and self-efficacy amongst patients with colorectal cancer and how these changed throughout the duration of their initial treatment for cancer following diagnosis. It was important, therefore, that an approach was chosen which would enable these perceptions to be explored from the perspective of patients engaging in self care and which would allow these perceptions to be explored using different research methods, specifically from both qualitative and quantitative angles. Furthermore, given the gaps in the current evidence base in which research has predominantly been cross sectional, it was valuable to focus longitudinally on how patients' perceptions and experiences changed throughout the duration of their treatment for cancer.

This chapter concentrates on the value of adopting a longitudinal, patient-focussed approach and why this approach is fundamental for researching and promoting patients' involvement in self-care. This is an approach that emphasises the importance of the patient and their unique perceptions and experiences, and the ways in which these change over time, as being at the heart of their involvement in self care. The following discussion builds on the arguments made in Chapters 3 and 4, calling for greater consideration of qualitative research on perceptions and experiences of self care, control and self efficacy in patients with cancer, how these change throughout the duration of patients' treatment and the importance of identifying those factors which may influence their involvement in self care. Finally, the value in adopting a longitudinal, patient focussed approach within the current research study and the ways in which the previous discussions have informed and guided the use of this approach are considered.

5.2 The Importance of a Patient Focussed Approach

The emphasis within current health policy, pledging support for promoting and supporting patients' involvement in self-care raises a number of issues. In particular, the previous chapters highlighted that the quality of the evidence base is, at present, insufficient to underpin the level of support for involving all patients in self care and the methods by which to support and sustain their involvement. Typically, research on self care has followed a quantitative approach to ascertain the outcomes of being involved in self care and the effectiveness of interventions, designed to promote involvement in self care, on a range of patient outcomes (for example, see Chapter 3, Tables 3.4 and 3.5). Although useful for contributing to a robust evidence base on the nature of self-care, these interventions, designed to promote involvement in self care, have typically favoured a blanket approach, where all patients are treated the same. They seem to assume that by furnishing patients with self care information and skills training, they will understand the importance of their involvement in self care and thus, engage in more self care (Paterson et al, 2001; Kralik et al, 2004). As the recent evaluation of the pilot phase of the UK Expert

Patient Programme (EPP) found, however, a generic, 'one size fits all' approach to the content and delivery of the course was problematic since it was too rigid to respond to individual patients' needs and that patients, therefore, could not relate to it (Kennedy et al, 2005).

Hence, it is apparent that current approaches to promoting involvement in self care have often failed to acknowledge the value of focussing on the individual patient and the importance of considering their unique perceptions and the influences that are likely to shape their involvement in self-care. In relation to patients with cancer, this means that little is known about what self-care actually means to patients with cancer, the complexities associated with the process of them actually being involved in self-care and how this, and their perceptions, change during their treatment phase. This calls for an approach which takes a more dynamic view of self care (Dill et al, 1995) – one which acknowledges and emphasises the individuality of patients, and which seeks to explore their unique experiences of being involved in their self care and what this means to them.

The discussions in Chapter 3 alluded to the value of conducting qualitative research on patients' perceptions of self-care in order to provide a deeper understanding of their involvement in self-care and how this can be supported. In particular, the findings from qualitative research in patients with hypertension (Sims, 1999) and heart failure (Riegel and Carlson, 2002; Horowitz et al, 2004) has offered a valuable insight into the meanings that people ascribe to self care, their beliefs surrounding their own involvement in self care and the rationales behind their involvement and non-involvement in self care. Such research, although not intended to be generalisable to wider populations as such, is valuable for exploring the patterns of patients' involvement, or non-involvement, in self care and highlights the potential for qualitative research in creating a mechanism for articulating patients' unique perceptions and experiences. Furthermore, the information obtained from qualitative research offers a greater understanding of the complexities associated with

patients' involvement in self care and as Davidson et al (2004) claims, provides fundamental information that caregivers and health professionals can draw on to collaborate with patients in helping them to develop their self care abilities. The research team at the National Primary Care Research and Development Centre, University of Manchester, who are conducting the next phase of the evaluation of the Expert Patient's Programme, have also acknowledged the importance of adopting a patient-focussed approach and aim to explore qualitatively how individuals become involved in self care and how they manage their condition prior to and following attendance at an EPP course in their ongoing evaluation of the EPP (National Primary Care Research and Development Centre, 2007). Notably, however, there are fewer studies of this nature conducted in patients with cancer to extrapolate some of these issues in relation to their involvement in self care. Subsequently little is known about their perceptions and experiences of being involved in self care, and whether this changes throughout the duration of their treatment.

There is a plethora of quantitative research which has suggested that patients' involvement in self care is linked to greater perceptions of control and self efficacy (for example, in patients with arthritis and other chronic illnesses (Taal et al, 1996; Lorig et al, 1993, 1999; Barlow et al, 2000; Lorig et al, 2001; Skinner and Hampson, 2001; Lorig et al, 2003; Wright et al, 2003; Lorig et al, 2005) and a handful of studies in patients with cancer (Taylor et al, 1983; Henderson and Donatelle, 2003). However, given the quantitative nature of these studies, little is known about the unique perceptions of control and self efficacy that patients with cancer hold, and the ways in which these perceptions may influence their attempts to gain control and their involvement in their self care throughout the duration of their treatment. One study, which illustrates the value of using a patient focussed approach, adopting a qualitative methodology for investigating perceptions of control amongst patients with cancer and the ways in which they attempt to gain control over managing the effects of their illness, is a phenomenological study in patients (n=7) with haematological cancer conducted by Bulsara et al (2004). The findings from semi

structured interviews, conducted with patients and their spouses, identified the significance of perceived control for these patients, highlighting that patients had a strong determination to remain in control of the effects of their illness and its' treatments. They also revealed the ways in which patients attempted to gain control over the effects of their illness through acceptance of their diagnosis, maintaining a positive outlook, the support from family and friends and health professionals and through sharing their experiences with fellow patients who also had cancer. Although, the findings from this study cannot be generalised because of the small sample, Bulsara et al (2004) identified that having a sense of control over the effects of cancer and its' treatments is a very individual and unique experience and a qualitative methodology, such as the one they chose, provided a detailed understanding of the importance of perceived control to these patients and the ways in which they attempted to gain control following a diagnosis and during treatment for cancer.

In summarising the above discussion, the current evidence base and the policy recommendations made in relation to self care, are weakened by a failure to focus on the individuality of patients. In particular, there is a lack of consideration of the *meanings* that patients ascribe to self care and a lack of recognition about the *uniqueness* of their perceptions and experiences of self care and the implications that all of this has for their involvement. Furthermore, the predominance of cross sectional, quantitative methodologies amongst existing research on the nature of self care, perceived control and self efficacy, highlights the need for an approach which focuses on understanding the individual; the reasons why patients become involved in self care; how they become involved and the personal factors which influence their involvement in self care over time. It is essential that such an approach places patients at the centre of self care, by drawing on the principles from qualitative methodologies, to provide a fuller understanding and to enable patients' unique perceptions and experiences of self care, control and self efficacy to be extrapolated. The findings from previous qualitative work on self care (Sims, 1999; Riegel and Carlson, 2002; Horowitz et al, 2004) and on perceived control (Bulsara et al, 2004) have served to

reinforce the value of this approach in contributing to understanding the individuality of patients and the implications of this for their involvement in self care. This approach, which emphasises the patient as the focus of the investigation, may be termed a 'patient-focussed approach'. The following section considers the relevance of this approach to the current research study and why this approach, involving a combination of qualitative and quantitative methods, was chosen.

5.3 A Mixed Method Approach

The current study, following a patient-focussed approach, involved a combination of qualitative and quantitative methods to explore patients' perceptions and experiences of being involved in self care and their perceptions of control and self-efficacy. The qualitative component of the study formed the main part of this investigation since little exploratory work has been conducted in relation to the involvement of patients with cancer in self-care. This approach is important for attempting to find out what is happening in little or poorly understood situations, to seek new insights and to raise new questions to be investigated (Robson, 2002). Little remains known about the significance of psychological constructs such as perceived control and self-efficacy, how these change over time and how these contribute towards encouraging involvement in self-care amongst patients with cancer. However, since the degree of change in a phenomena is more easily measured over time using quantitative methods (King, 2001), the inclusion of a quantitative component in the study was considered to be important and important for broadening the investigation in the current study. Combining both these approaches allowed the patient's perspective to form the central focus of the investigation and allowed their perceptions and experiences to be investigated from different dimensions in order to provide a broad understanding of patients' perceptions and experiences of control, self efficacy and involvement in self care.

In exemplifying the value in using a mixed method approach, Lansbury (2000), in her study of older adults' perceptions towards chronic pain management, also identified that different

perceptions of a phenomena can emerge between qualitative and quantitative methodologies and consequently, this may contribute to a fuller, more complete understanding of patients' involvement in self-care. In relation to diabetes self care, Anderson (2003) acknowledged that whilst a quantitative perspective allows researchers to attain a certain level of precision and objectivity, the descriptions and interpretations obtained by combining these findings with a qualitative perspective, can help to provide a faithful representation of the patients' lived experience and a more complete knowledge base, for example, about self care. A mixed method, patient-focussed approach was, therefore, considered an appropriate methodology for the current research study since research relating to involvement in self care amongst patients with cancer has never before attempted to provide an in-depth understanding of perceived control, self efficacy and involvement in self care from the patient's perspective using both qualitative and quantitative approaches. Subsequently, the study provides a fuller appreciation of how both methods contribute to a better understanding of self-care.

Furthermore, since the intention of the current study was to provide an understanding of how patients' perceptions and experiences of control, self efficacy and involvement in self care changed over the course of their treatment, a longitudinal approach was considered essential. The following discussion highlights the significance of this approach in relation to the gaps in the current evidence base and its' role within the current study.

5.4 A Longitudinal Approach

There is little existing research which has investigated both patients' perceptions of control and patients' involvement in self care from a longitudinal perspective. Chapters 3 and 4 highlighted that previous studies on self care, illness perceptions, including perceived control, and self efficacy have largely been cross sectional. Such research has, therefore, tended to provide a "snap-shot" of events at one point in time or over a relatively short period of time. In the case of many of the self care interventions studies, it was identified

that these periods have been as short as six weeks (Miaskowski et al, 2004), and no longer than five months. Willett et al (1989) claim that individual change is a process that takes place continuously over time and comparison of 'before' and 'after' changes, as in many of the self care intervention studies discussed earlier, are not the most subtle or effective ways to reveal features of any changes that occur. As a result, such research has done little to enhance our understanding of how and why patients' perceptions of control, self efficacy and involvement in self care change over time, for example, during the course of a six month treatment of chemotherapy and how patients perceptions of control and self efficacy help to shape their involvement in self care during this time. It is these gaps which led the researcher to employ a prospective longitudinal research design in the current study.

Longitudinal studies are valuable for helping to provide a more realistic and detailed account of patients' behaviours and how these change (Ruspini, 2000) and depending on the approach used, can avoid the difficulties associated with retrospectively collecting data and patient recall (Robson, 2002). With particular relevance to self care and the factors which influence patients' involvement, Paterson and Thorne (2000) acknowledged that amongst patients with chronic illness, responses towards self care are likely to change over time, as patients encounter new challenges and learn how to cope with these (Paterson and Thorne, 2000). Self care has also been highlighted as being a developmental process, which is learned by patients over a considerable period of time (Orem, 1991) and that involvement in self care decision making is not a static, one time event, but an ongoing process which is likely to change over time (Paterson et al, 2001). Furthermore, it is likely that patients' perceptions of control and self-efficacy may change over time as well. As such, these perceptions may produce changes in the patterns of patients' subsequent involvement in self care.

Ultimately, it is clear that patients' involvement in self care and the factors which influence and affect their involvement, cannot be viewed in terms of a one off or short term

experience, as it has previously been assumed. What's more, since it cannot be assumed that self care is a static process, the factors that influence patients' involvement also cannot be assumed to be static and unchanging over time. Rather, what is clear from existing research is that there is a greater need to explore the process of self care, and the factors that influence patients' involvement in self care, from a longitudinal perspective, in order to provide a realistic and accurate understanding of patients' involvement in self care.

5.5 Overall Summary of Chapter

In summary, this chapter has highlighted the rationales for adopting a patient focussed, mixed method, longitudinal approach and its value within the current study. In particular, this approach has been employed in response to many of the flaws within existing research, which have failed to acknowledge the importance of the individual patient, the meanings that they ascribe to self care, and the personal factors which influence their involvement in self care; the ways in which patients' perceptions of control, self efficacy and self care change over time; and the predominance of studies which have given precedence to a quantitative methodology, rather than accepting the value in using a greater range, and combination, of approaches, for example, qualitative methodologies. The following chapter continues by considering the methods employed within the current study in greater detail. In particular, the following chapter focuses on the design and methods of the study, as well as the aims and research questions, and the sample of patients recruited to the study.

Chapter 6 Methods

6.1 Introduction

The purpose of the research for this doctorate was to explore perceptions and experiences of control, self-efficacy and involvement in self-care amongst patients with colorectal cancer and how these changed from the beginning to end of a six-month course of chemotherapy treatment. The previous chapter highlighted that a longitudinal, mixed method, patient-focussed approach was chosen in this study and that this was important to enable patients' perceptions and experiences of self care to become the central focus of the study. In addition the use of both qualitative and quantitative methods allowed these perceptions and experiences to be explored both narratively and numerically, for the purposes of complementarity and for achieving a broader understanding of patients' perceptions and experiences of being involved in self care, and their perceptions of control and self-efficacy, than has been identified in previous research.

The current study was undertaken in patients receiving chemotherapy treatment for colorectal cancer in one clinical site in Scotland, UK. Qualitative semi-structured interviews formed the main focus of the investigation to explore patients' perceptions and experiences of being involved in self care, their meanings of self care, how their involvement in self care changed at the beginning and end of their treatment and whether this was associated with their perceptions of control and self efficacy. Quantitative questionnaires and structured self care diaries were also used to quantify changes in, and associations between, the degree of patients' involvement in self care and their perceptions of control and self-efficacy. The following chapter considers the methods chosen for the current research study including a discussion of the aims, research questions and hypotheses (for the quantitative data) of the study, the sample of patients recruited to the study, and the design, methods and analysis strategies utilised to ensure that the aims of the study were met.

6.2 Aim of the Study

The aim of the study was to explore perceptions and experiences of being involved in self care and perceptions of control and self-efficacy over time amongst patients receiving a six month course of chemotherapy treatment for colorectal cancer.

6.3 Research Questions

In attempting to meet the aim of the study, specific research questions were devised:

1. How do patients describe the meaning of self care and their involvement in self care and what are their perceptions of control and self-efficacy between the beginning and end of their course of chemotherapy treatment for cancer?
2. Does patients' degree of involvement in self care, and perceptions of control and self-efficacy change between the beginning, middle and end of their course of chemotherapy treatment?
3. Is patients' degree of involvement in self care associated with their perceptions of control and self efficacy at the beginning, middle and end of their course of chemotherapy treatment?

In relation to these research questions, it was hypothesised that:

1. The degree of self care carried out by patients and their perceptions of control and self efficacy will increase from the beginning to end of their chemotherapy treatment, and;
2. Patients who report a high level of control and self efficacy will carry out a greater degree of self care

6.4 Theoretical Framework

Leventhal's Self Regulation Model, which posits individuals develop their own common sense beliefs or perceptions about their illness which they use to make sense of and understand their illness and which determine their behaviour, was chosen as the theoretical

framework for the current study. This framework was chosen because it has been found to reliably predict patients' involvement in self care, health promoting behaviours and adherence to medications (Cameron, 1997; Horne and Weinman, 1999; Searle and Murphy, 2000; Horne and Weinman, 2002; Henderson and Donatelle, 2003; Llewellyn et al, 2003), and because of its patient focus and ability to provide an understanding of patients' experiences and perceptions of their illness and its management. Furthermore, it has been tested in patients with cancer (Leventhal et al, 1986; Buick, 1997; Cameron, 1997) and includes key components that were of particular interest in this study, namely, perceived control. The framework was used to guide the choice of data collection instrument for quantitatively measuring perceived control (the Illness Perception Questionnaire (revised) (Moss Morris et al, 2002) and to broadly guide the development of the qualitative semi-structured interview guides for exploring patients' narrative accounts of meanings of self care, their involvement in self care and their perceptions of control and self-efficacy between the beginning and end of their treatment. The interview guides are shown in Appendices 6 and 7 and its structure in relation to Leventhal's Self Regulation Model is discussed further in section 6.9.8.1.

6.5 Study Design

A patient-focussed, mixed method, longitudinal approach was adopted in this study. The previous chapter emphasised the importance of this approach to the aim, research questions and hypotheses guiding the study. The quantitative approach was used to collect and quantify data on changes in the degree, and types, of self care carried out by patients and changes in their perceptions of control and self efficacy between the beginning and end of their treatment. The qualitative approach, focussing on a smaller sub sample of patients participating in the full study, was used to gather and interpret data on patients' lived experiences of being involved in self care and the meanings that they ascribe to self care and the importance of their perceptions of control and self efficacy during their treatment. Ultimately, the researcher considered that although the qualitative component was the

dominant approach, both the qualitative and quantitative components functioned as complementary strands and strengthened the study findings since the qualitative findings and were able to elaborate and expand on and offer explanations for the quantitative findings. Thus it was intended that this approach would be able to offer a broad, rich and in depth understanding of how both methods can contribute to a better understanding of patients' involvement in self-care. The following discussion further considers the debates surrounding the use of mixed methods research and considers some of its challenges in relation to the current study.

6.5.1 Mixed Methods Research

Tashakkori and Creswell (2007) broadly define mixed methods research as “research in which the investigator collects and analyses data, integrates the findings and draws inferences using both qualitative and quantitative approaches” (p3). In particular, mixed methods research is important for bringing together qualitative and quantitative findings in forging an overall or negotiated account of the findings, which may otherwise not have been gleaned by using one approach alone (Bryman, 2007). The integration of qualitative and quantitative findings is also important for comparing the similarities and differences between aspects of human behaviour and is a powerful way to find out more about a particular phenomenon (Bernardi et al, 2007).

Theoretically, however, the integration of qualitative and quantitative research continues to be debated. In particular, the different epistemological and ontological assumptions and paradigms associated with qualitative and quantitative research have had a major influence on discussions over whether the integration of the two is feasible, let alone desirable (Sale et al, 2002; Morgan, 2007). Qualitative and quantitative research is said to differ in far more than simply the use or absence of numbers and measurement but more so in respect to their epistemological and ontological foundations (Bryman, 2004). In particular, quantitative research can be construed as a research strategy that emphasises quantification

in the collection and analysis of data and is based on an epistemological position of positivism which advocates that causal explanations of a phenomenon can be provided through the application of the methods of the natural sciences to the study of social reality (Bryman, 2004; Mackenzie and Knipe, 2006). Epistemologically, the researcher and the research are viewed as separate entities, thus the researcher is capable of studying a phenomenon without influencing it or being influenced by it (Sale et al, 2002). Furthermore, quantitative research embodies an ontological position of objectivism, which views that there is one truth, an objective reality that exists independent of human perception and social interaction (Sale et al, 2002; Bryman, 2004) and entails a deductive approach in which its purpose is to test theory (Bryman, 2004).

In contrast, qualitative research can be construed as a strategy that emphasises language, processes and meanings rather than quantification in the collection and analysis of data and incorporates an epistemological position of interpretivism, which advocates the application of methods that are fundamentally different from those based on a positivist position and which seek to interpret how individuals experience and make sense of the world around them (Sale et al, 2002; Bryman, 2004; Mackenzie and Knipe, 2006). An interpretivist epistemology recognises the role of interaction between the researcher and the research participants (Guba and Lincoln, 1994; Mason, 2002). Furthermore, qualitative research embodies an ontological position of constructionism which challenges the objectivism view that organisation and culture are pre-determined and not influenced by social interaction, and perceives that there are multiple realities or truths based on one's construction of reality which are in a constant state of change (Sale et al, 2002; Bryman, 2004). Hence, qualitative research is based on a position which views its goal as being to explain and understand the subjective experiences of individuals' social realities. In contrast to quantitative research, qualitative research entails an inductive approach in which its purpose is to generate theory, rather than to test it (Bryman, 2004).

Hence, the polarisation between the epistemological and ontological perspectives inherent in both qualitative and quantitative approaches has led purists of a mono-method approach (for example, Smith, 1983, Smith and Heshusius, 1986, Schrag, 1992, Lincoln and Guba, 2000, Sale et al, 2002, and Maxwell and Delaney, 2004) to believe that they are incompatible and argue that the integration of qualitative and quantitative research methods is not feasible and is undesirable (Sale et al, 2002; Onwuegbuzie and Leech, 2005). For example, purists of a positivist approach suggest that the essence of science is objective verification and that their findings rely on the use of objective methods (Onwuegbuzie, 2002). Purists of an interpretivist approach argue that time and context free generalisations, associated with the positivist paradigm, are neither desirable or feasible and that it is impossible to fully differentiate causes and effects (Guba, 1990). Furthermore, Sale et al (2002) argue that quantitative and qualitative methods cannot be combined since they serve to investigate different types of phenomena, for example, quantitative research is unlikely to be able to access the lived experiences of patients.

The differences between quantitative and qualitative research extend beyond their philosophical debates. In particular, Sale et al (2002) note that quantitative and qualitative approaches differ in terms of the methods employed in their enquiries. Quantitative methods, in line with their positivist and objective epistemological and ontological perspectives, employ methods which typically standardise participants' responses and curtail the ability to extract in depth data about perceptions and meanings (Dill et al, 1995), and typically recruit larger sample sizes in an attempt to represent the wider population (Sale et al, 2002). On the other hand, qualitative methods, in line with their interpretivist and constructionist epistemological and ontological perspectives, employ methods which allow an in-depth focus on individuals' unique realities, experiences and perceptions (Dill et al, 1995) and typically involve the recruitment of a smaller, purposeful sample which are not meant to be representative per se but which can be used to provide detailed and important information (Reid, 1996). Furthermore, Sale et al (2002) comment that

qualitative and quantitative methods differ in terms of the sources of funding that both attract, the different expertise that each offers to researchers and research teams, and the different styles of language used to describe them. They use the term ‘observational work’ to exemplify their point in which they claim refers to case control studies in a quantitative context but in a qualitative context, it would refer to an ethnographic immersion in a particular culture (Sale et al, 2002).

However, proponents of mixed methods research, also referred to as ‘pragmatists’, suggest that the purist view, that quantitative and qualitative approaches cannot be merged, poses a threat to the advancement of science (Onwuegbuzie and Leech, 2005) and that whilst epistemological and ontological commitments may be associated with certain research methods, as described above, the connections are not necessary deterministic (Bryman, 2004). Rather than being seen as a replacement to qualitative and quantitative approaches, Johnson and Onwuegbuzie (2004) view mixed methods research as an approach which draws upon the strengths and perspectives of each method, recognising the existence and importance of the physical, natural world as well as the importance of reality and influence of human experience. Indeed, Onwuegbuzie and Leech (2005) acknowledge that there are in fact overwhelming similarities between quantitative and qualitative perspectives which can help to promote perceptions of their compatibility. In particular, both methodologies attempt to derive meaning from the interpretation of their data, whether it be by numbers or by words, both use analytical techniques designed to offer maximal meaning from their data and both employ techniques to enhance validity and minimise bias (Onwuegbuzie and Leech, 2005). Thus, rather than being polar opposites, Newman and Benz (1998) describe quantitative and qualitative research as an interactive continuum since neither tradition is independent of each other nor can either tradition encompass the whole research process (Onwuegbuzie and Leech, 2005).

In supporting this view, Bryman (2004) asserts the view that it is feasible to combine qualitative and quantitative methods without violating the philosophical principles traditionally attached to each method, whilst Brannen (2005) claims that methodological decisions are often made based on practical reasons such as skills and resources, rather than theoretical reasons. Pragmatists, who favour mixed methods research, acknowledge that mixed methods research is an approach which is not committed to any one particular philosophy but rather advocates the use of whichever philosophical or methodological approach works best for a particular research problem (Robson, 2002; Creswell, 2003).

The concept of mixing methods was introduced within social science research by Jick (1979) and was seen as a means for seeking convergence across qualitative and quantitative methods (Creswell, 2003). Since then, however, there has been an explosion in the use of mixed method designs used for a number of different purposes. In particular, Greene et al (1989) and Brannen (2005) highlight four further purposes of mixed methods studies including: (i) complementarity, in which the findings of one approach is intended to elaborate, enhance, and illuminate the findings from another approach, (ii) development, in which the findings from one approach are used to inform the findings of another approach, (iii) initiation, where both approaches are used to discover paradoxes and contradictions, and (iv) expansion, where different approaches are used to expand the breadth and range of enquiry. Several researchers have also noted that mixed method research can be useful in some areas of research, such as nursing or health promotion, because the complexity of the phenomena requires data from a large number of perspectives, such as those derived from a mix of qualitative and quantitative approaches, and requires the use of a broad spectrum of qualitative and quantitative methods (Clark and Yaros, 1988; Steckler, 1992). Creswell et al (2005) also claim that using mixed methods can help researchers to better frame those issues in need of further investigation and more saliently identify the variables of interest or significant to particular populations.

Indeed, the researcher considered these issues to be relevant to the level of enquiry required in the current study for understanding patients' involvement in self care. Hence, although the researcher acknowledged the debates surrounding the use of mixed method research, a mixed method approach was adopted in the current study for complementarity and expansion purposes in using the qualitative findings to enhance and elaborate and expand upon the quantitative findings (Greene et al, 1989; Brannen, 2005) and to expand the breadth and range of the investigation into patients' involvement in self care (Greene et al, 1989; Brannen, 2005). In particular, in the current study, the researcher wanted to investigate patients' involvement in self care using a patient-focussed approach but from different perspectives, thus, expanding the breadth and range of the investigation ('expansion', Greene et al, 1989; Brannen, 2005), in order to develop a realistic understanding of patients' involvement in self care and their perceptions of control and self efficacy.

The researcher also wanted to quantify, and determine associations between, changes in the degree of self care, and the types of self care activities carried out by patients and changes in their perceptions of control and self efficacy between the beginning and end of their treatment and to compare and contextualise these findings with the qualitative data to explore the lived experience of self care ('complementarity', Greene et al, 1989; Brannen, 2005). In particular, the researcher considered that the qualitative findings would complement the quantitative findings in terms of offering an understanding of how patients made sense of their involvement in self care, and changes in their involvement in self care, and the importance of their perceptions of control and self efficacy and how these influenced their self care behaviours. In using a mixed method approach for the purposes of expansion and complementarity, the researcher intended to determine the value of the contribution that both qualitative and quantitative approaches, when integrated, made towards the evidence base in terms of offering a greater understanding of patients' perceptions and experiences of being involved in self care, and their perceptions of control

and self efficacy during their six month course of chemotherapy treatment, than using one approach alone.

6.5.2 Challenges of Mixed Methods Research

Mixing methods, however, is not simply a case of joining together two techniques (Pope and Mays, 1995) and its use poses some challenges for researchers. Several researchers have noted that integration of qualitative and quantitative approaches is challenging because of the different epistemological and ontological perspectives inherent in each approach and the use of different data collection instruments (Sim and Sharp, 1998; Wendler, 2001; Bryman, 2007). Bryman (2007) also identified several further barriers to the integration of qualitative and quantitative findings including, favouritism towards a particular approach or set of findings, meaning that researchers typically emphasised the one set of findings that they saw as being the predominant aspect of their study or those findings that they were most familiar and confident with and, therefore, the findings were not combined in a way that was mutually illuminating; and, the fact that few good quality examples of integrated approaches exist within the literature and hence, there is uncertainty about the best approach to integrating qualitative and quantitative findings. Indeed, the latter point in particular was a issue for consideration in the current study. Bryman (2007) concluded, however, that an aid to linking the analysis of qualitative and quantitative findings is not to lose sight of the rationale for conducting the mixed methods study in the first place.

For integrating the qualitative and quantitative findings in the current study, the researcher used the guidance provided by a number of researchers (Foster, 1997; Onwuegbuzie and Teddlie, 2003; Happ et al, 2006) since there was published evidence of their approaches to data analysis and integration and these seemed most relevant to the purposes for this mixed method study. The approach adopted in the current study was known as a ‘concurrent nested approach’ in which both methods are used but one in particular predominates and one has a lesser emphasis but is clearly embedded within the more dominant approach. In

this study, the qualitative component was the predominant approach yet both approaches were carried out concurrently, whilst their findings have been integrated and written up in Chapter 11 in such a way that the qualitative and quantitative findings were mutually illuminating and offered a broader perspective of patients' involvement in self care, as is the purpose of this type of mixed method design (Tashakkori and Teddlie, 2003; Happ et al, 2006). The stages involved in the analysis of both the qualitative and quantitative findings and their integration is discussed in further detail in section 6.11.

6.5.3 Longitudinal Approach

Chapters 3, 4 and 5 identified that little is known about how patients' involvement in self care and their perceptions of control and self efficacy change over time, and with specific reference to the context of this study, how these variables change from the beginning to end of a six month course of chemotherapy treatment. Previous research on self care, control and self efficacy has largely been cross sectional, meaning that these study findings have only provided a "snap-shot" of events at one point in time or over a relatively short period of time. In particular, patients' perceptions and experiences of self care, control and self efficacy may differ from the beginning of their treatment to end of their treatment as they encounter new challenges or experiences during their treatment and learn how to prepare, cope with and manage these (Paterson and Thorne, 2000). Hence, to determine this in the current study, a longitudinal approach, following patients from the beginning to end of their six month course of chemotherapy treatment, was adopted.

Mingione (1999) claims that longitudinal designs are particularly appropriate for studies which use a mixed method approach, since neither aspect, when used alone, may be sufficient to produce an accurate picture of the phenomena under investigation. Whereas cross sectional studies involve the collection of data at one point in time and are often retrospective (Polit and Hungler, 1998; Robson, 2002), longitudinal designs involve the collection of at two or more time points and are usually prospective (Polit and Hungler,

1998; Menard, 2002), and the analysis refers to comparison of that data between these points (Ruspini, 2000). Longitudinal designs are thus deemed superior to cross sectional designs in terms of their ability to detect patterns of change over time and for avoiding problems with retrospective data collection and relying on patients' recall of events, which may be inaccurate and unreliable (Singer and Willet, 1996; Robson, 2002), and in their capacity to describe the direction and magnitude of causal interpretations (Menard, 2002). Existing research has thus far failed to offer an in depth insight into patients' perceptions and experiences of being involved in self care and their perceptions of control and self efficacy which would be valuable in contributing to a greater understanding of these factors and their relationships. Hence, this study not only aimed to elicit a greater description and understanding of patterns of changes over time, but also to illuminate reasons behind these changes and patients' experiences.

All patients prospectively completed the quantitative measures on three occasions, at the beginning, middle and end of their six month course of chemotherapy treatment and a smaller sub-sample of patients completed qualitative interviews on two occasions at the beginning and end of patients' treatment. This approach allowed a great deal of information to be gathered over the duration of patients' treatment and using the three data collection points for the quantitative data was initially considered to be important for reflecting any changes in the variables between the beginning and middle or middle and end of patients' treatment, that patients would be asked upon in the second interviews, and also for providing a shorter lag time between data collection points, as noted in the following section.

6.5.4 Challenges of the Longitudinal Approach

The most significant problem in longitudinal designs is the potential loss of participants at different time points in the study (Polit and Hungler, 1998). This is known as attrition and is a problem since those who drop out of the study may differ in important respects from the

participants who continue and complete the study (Polit and Hungler, 1998). Hence, the representativeness of the sample and the internal and external validity of the study findings can be affected (Polit and Hungler, 1998; Ruspini, 2000). It is important to manage this by identifying any differences between these patients. The characteristics of the patients who completed the current study and those patients who withdrew during the study are compared for any differences in Chapter 7.

Attrition can also be caused by a long lag time between data collection points in a study (Polit and Hungler, 1998; Robson, 2002) and shorter time lags between data collection time points are generally considered to enhance the quality of the data obtained (Singer and Willet, 1996; Ruspini, 2000). Hence, the data collection time points decided upon in the current study were chosen based on the value of information that they would provide at each point (cycles 1, 3 and 6; beginning, middle and end of treatment), but also offered a relatively short lag time between data collection time points. The researcher also attempted to minimise the level of attrition expected within the study by ensuring that all patients who were approached were given a detailed yet straightforward verbal and written description of what the study would entail for them and were given the opportunity to ask any questions that they had.

Other potential limitations relate to the quality of data obtained in longitudinal studies. Repeated measures offer the facility for patients to act as their own controls since designs of this nature have the advantage of ensuring the highest possible equivalence between subjects (Polit and Hungler, 1998), and short time lags between data collection time points can help to enhance the completeness, reliability and validity of the data obtained (Polit and Hungler, 1998; Ruspini, 2000). King (2001), however, cautions that a longitudinal design can increase the potential for errors and missing data. These problems can affect the completeness, validity and generalisability of the study findings. In attempting to minimise the potential for errors and missing data within the data sets, the instructions for completing,

and the layout of, the data collection instruments were kept simple to avoid confusion and promote consistency in completion of the instruments. Missing data was managed in accordance with the guidance provided by Loewenthal (2001) who stated that in cases where there were few missing data, for example, less than 40% of missing items in a subscale, the item can be substituted with the mean value for that variable. Menard (2002) states that this is likely to be more appropriate than simply deleting the case with the missing data from the analysis. Further discussion of how this related to the current study is given in Chapter 8.

The researcher also acknowledged that, as pointed out by Menard (2002) the quality of data in a longitudinal study can be affected by repeated contact between researchers and participants. Although repeated contact is inevitable in a study of this nature, it was also considered to be helpful in tracking patients and preventing avoidable attrition (Menard, 2002). A fuller discussion of the potential for bias in a longitudinal study can be found in section 6.10.

The following sections consider the sample recruited to the study, including a consideration of the clinical site in which the research was conducted, the sampling strategy and sample size, the eligibility criteria for the sample and the process of recruitment.

6.6 Population

6.6.1 Clinical Site

The study was conducted in one clinical site, namely the Beatson Oncology Centre, in Glasgow, Scotland. This site was primarily considered for the location of the study since it offers both local and regional, inpatient and outpatient oncology services and is the largest specialist cancer centre in Scotland. There are approximately 250 new patients attending the colorectal cancer clinic each year which accounts for 40% of all consultations at the colorectal cancer clinic.

6.6.2 Sampling Strategy and Sample Size

A consecutive, convenience sampling strategy was employed in recruiting patients to the study since the researcher acknowledged that a range of treatment options were presented to patients at the clinic and hence, the researcher intended to approach as many patients as possible who were offered the Mayo Clinic Regimen during the recruitment period. Although the current study followed a mixed methods approach, the focus of the study was to elicit the patients' perspective and, therefore, the predominant focus was the qualitative data, supported by the quantitative data to help identify changes over time in each of the variables and to broaden an understanding of patients' perceptions and experiences of their involvement in self care. As identified in the literature on sampling in a mixed method study, it was appropriate in this design to recruit a large sample which would be appropriate for obtaining meaningful quantitative data and then select a subsample of this population with which to conduct the qualitative work (Tashakorri and Teddlie, 1998; Kemper et al, 2003; Collins et al, 2006; Collins et al, 2007).

The primary outcome measure on which the power calculation for the sample size was based was the number of days on which patients reported that they had carried out self care (the degree of self care carried out) (range 0-28) as measured by the self care diary. It was hypothesised that the degree of self care that patients carried out would increase incrementally across the three time points. Ideally, the power calculation and the desired effect size for this study would have been informed by the findings from previous research. A rigorous review of the literature on self care, however, found no existing studies which had used this as a primary outcome variable and, indeed, had measured this longitudinally over the duration of a full month as was the intention of the self care diary used in this study in measuring this outcome. Therefore, the power calculation that was conducted was somewhat speculative and was limited given that there was no previous work to inform whether a large or small effect could be expected. Consequently, the researcher set out to try and detect a conservative effect size that would be appropriate for the numbers of new

patients that were being seen at the clinic per month and thus the likely numbers of patients who may participate in the study. The researcher, therefore, set out to detect a small effect size ($f=0.2$) which, with a power of 0.8 (alpha 0.05) in a three repeated measures, within subjects design, identified that a sample size of 42 patients would be required (G*Power, 2007). Given that there were 250 new patients being seen at the colorectal cancer clinic each year (on the advice of staff at the clinical site where the research was being conducted), it seemed reasonable that it would be possible to recruit 55 patients to the study which would allow for some attrition given the nature of the patient group being studied and the longitudinal design of the study. The pilot study was used to confirm whether the intended sample size was feasible (the results of which are reported in Chapter 7).

A convenience sub sample of patients from the full study sample were invited to participate in the semi structured interviews at the beginning and end of their treatment. The researcher believed that conducting interviews at two time points with the full sample would have been unfeasible since this was too large a sample for a qualitative investigation, in which smaller samples are deemed more appropriate (Coyne, 1997). In particular, Morse (1991) commented that techniques such as random sampling in qualitative research are not as appropriate since samples for qualitative research tend to be smaller and participants are selected on the basis of particular characteristics or their willingness and ability to articulate and reflect on their experiences that will be useful for answering the research questions. Hence, since the rationale for a smaller qualitative sample is to interview participants which will ultimately generate a rich and broad understanding of a particular phenomena (Coyne, 1997), the researcher invited a smaller convenience sub sample of participants who were interviewed at two time points during the study. This subsample was intended to provide a rich and broad understanding of patients' perceptions and experiences of being involved in their self care and their perceptions of control and self efficacy throughout the duration of their 6 month course of chemotherapy treatment. The implications of employing a

convenience sampling strategy and the likely advantages in using an alternative sampling strategy in this study are further considered in Chapter 12.

6.6.3 Selection of the Sample

All patients who were identified as being eligible to participate in the study were approached by the researcher to consider taking part in the study. Table 6.1 details the eligibility criteria for the study.

| Inclusion criteria | Exclusion criteria |
|--|---|
| Diagnosis of colorectal cancer | Diagnosis of any other type of cancer |
| Beginning the 'Mayo' clinic chemotherapy regimen (Poon et al, 1989) | Not receiving the 'Mayo' clinic chemotherapy regimen (Poon et al, 1989) |
| Able to give written informed consent | Unable to give written informed consent |
| Deemed physically and psychologically <i>fit</i> to participate by any member of the healthcare team | Deemed physically or psychologically <i>unfit</i> to participate by any member of the healthcare team |
| Have a basic understanding of the English language | Do not have a basic understanding of the English language |

Table 6.1: Eligibility criteria for the study sample

Patients undergoing chemotherapy for colorectal cancer were chosen as the patient group to be recruited in this study since colorectal cancer is one of the most common forms of cancer in the UK, affecting both men and women of different ages and socio-economic backgrounds (Boyle and Langman, 2000). This allowed the researcher to recruit a patient group which would include a range of characteristics, in terms of gender, age and socio-economic background, to obtain as broad an understanding as possible of patients' unique and diverse perceptions and experiences of self care, control and self efficacy. Furthermore, little research of this nature has previously focussed on the experiences of this patient population, despite the growing importance of self care in this patient group which was highlighted in Chapter 2.

A homogenous sample of patients, who had been diagnosed with colorectal cancer and who were beginning the Mayo chemotherapy regimen (Poon et al, 1989), was recruited. This ensured, as far as possible, that all patients would be consistent in terms of the likely

duration of their treatment (6 cycles over a 6 month period) and the likely pattern of side effects that could have been experienced by patients during their treatment, and meant that the researcher could determine the true nature of changes in and associations between the variables in the study with less influence from extraneous variables (Polit and Hungler, 1998). Patients with other tumour types and receiving different chemotherapy regimens, other than the Mayo regimen, were excluded from the study, since the use of heterogeneous samples in previous research on self-care amongst patients with cancer has been identified as a limitation. Researchers have suggested that patients' perceptions and experiences of control may be influenced by clinical factors such as type of cancer, and stage, associated side effects and perceived severity of their disease (Taylor et al, 1984; Affleck et al, 1987; Watson et al, 1990). Furthermore, Ream et al (2005) acknowledged that a degree of heterogeneity within samples in studies of patients with cancer, for example, the inclusion of patients with different stages of disease or different tumour types, makes it difficult to determine who benefits most from participating in self care and in particular, the self care needs that patients have at specific points in their treatment journey. It is for these reasons that a homogenous sample was considered to be most appropriate.

Patients were recruited to the study when they attended for their first cycle of chemotherapy treatment. Patients had to be considered by clinical staff to be physically and psychologically competent to give written informed consent. Furthermore, as the questionnaires and diaries were written in English and the interviews conducted in English, patients had to have a basic understanding of the English language to be eligible to participate in the study.

6.6.4 Process of Recruitment

Eligible patients were identified from a review of the clinic lists generated by the clinical site and following discussions with clinical staff involved in the care of the patient, when they attended for their first clinic visit to discuss treatment options with their Consultant.

This may have introduced an element of bias to the study, because of the potential for ‘gatekeeping’ by clinical staff, which is discussed in section 6.10. The researcher was introduced to the patient who, at this time, offered them a written study information sheet (Appendix 1) and a verbal description of the study. Patients were informed that they were free to take the information sheet away to discuss it with significant others if they chose to do so. Patients were then approached when they attended for their first cycle of chemotherapy treatment (usually one or two weeks later) to find out if they had any further questions and if they wished to participate in the study. If patients were willing to participate they were asked to sign a written consent form (Appendix 2). Patients were also reminded that they could withdraw from the study at any time without their ensuing treatment and care being affected in any way. In addition, patients were given the contact details for the researcher and encouraged to contact her should they have any concerns about any part of the study. If patients declined participation into the study, they were thanked for their time and assured that the standard of their care or treatment would not be affected by their decision to decline participation in the study.

Guidance for informing how the process of recruitment should be conducted was obtained during the process of seeking ethical approval for the study and in negotiating access to the clinical site and study participants from key clinical staff. The following sections consider these processes and the ethical considerations relevant to the current study.

6.7 Access to the Clinical Site

The study proposal was initially discussed with several key staff at the clinical site, including the Consultant Oncologist, responsible for the colorectal clinic, and the Chief Nurse. It was important for them to critically review the study using their knowledge of that particular clinical setting and patient group, and to ascertain their willingness to allow the researcher to access the clinic and approach eligible patients to consider participating in the study. The researcher discussed the study with staff in the outpatient department, where

the study took place, as it was important that they became familiar with the researcher and were aware of the nature of the research that was being conducted and its' eligibility criteria. This was important since the clinical staff were then able to alert the researcher to eligible patients and were able to help minimise the number of patients that were missed by the researcher. Clinical staff involved in the study were regularly updated on the progress of the research and any changes in its conduct for example, the staff were informed as to the progress with recruitment and whether this was on target.

6.8 Ethical Considerations

The study was conducted in accordance with the approval received from the internal ethics committee at the University of Stirling, the Department of Nursing and Midwifery Research Ethics Committee, and the local research ethics committee at the clinical site, the Glasgow West Research Ethics Committee. A summary of the ethical considerations in this study, relating to the patient population, the study design and methods, and conduct of the study are considered in the following discussion.

In relation to the patient population, it was acknowledged that patients were being approached to consider participating in the study shortly after receiving a diagnosis of colorectal cancer. Many patients had undergone surgery and were anxious at the thought of beginning chemotherapy treatment. All patients were approached by the researcher in a sensitive manner and were given a full description of what the study entailed. Owing to the longitudinal nature of the research, and to ensure that patients did not feel pressured to participate in the study, patients were reminded that their participation was entirely voluntary and that they could decline participation or withdraw at any stage of the study, without it adversely affecting the treatment or standard of care that they received. Although there were no noted instances of distress caused to patients by their participation in the study, it was also important for the researcher to be aware of the potential for distress that

patients may have experienced because of their participation in the study and to give thought on how this would have been appropriately managed.

In accordance with the regulations set out in the Data Protection Act (1989), it was essential to ensure that all documentation, reports and publications relating to the study did not contain any identifiable details about patients participating in the study. All patients who consented to participate in the study were given a unique study number from which patients could not be identified by anyone other than the researcher and were assured that their responses were confidential and that their anonymity would be protected. Furthermore, it was important to ensure that personal details were stored securely in a locked filing cabinet which could not be accessed by anyone other than the researcher. It is intended that data collected during the study will be archived according to University of Stirling regulations for ten years.

Data collection began once necessary ethical approval had been obtained and access arrangements agreed. The data collection period began with the pilot phase, which was then followed by the active recruitment and ongoing, data collection phases as part of the main study. The following section describes the processes involved in data collection during the study, including the phases and schedule of data collection, and the methods and instruments used.

6.9 Data Collection

6.9.1 Phases of Data Collection

Data collection took place from October 2004 to December 2006, and consisted of three phases; the pilot phase, the active recruitment phase and the ongoing, data collection phase. The pilot phase, in which the feasibility and acceptability of the recruitment process, sample selection and methods and instruments were tested and refined, was conducted from October 2004 until February 2005. These results are reported in Chapter 7. The active

recruitment phase lasted 15 months and was conducted from March 2005 until June 2006. The ongoing data collection phase continued to run until December 2006. This final 6-month period provided a lag time for patients who had consented to participate in the study during the final month of the recruitment phase, in June 2006, and allowed them the appropriate length of time to complete their chemotherapy treatment and subsequently complete the data collection instruments.

6.9.2 Schedule for Data Collection

The following discussion outlines the time points at which the demographic, qualitative and quantitative data were obtained in the study. Table 6.2, at the end of this section, offers a summary of the time points at which the demographic data was obtained and the time points at which patients were required to complete the quantitative instruments and participate in the qualitative semi structured interviews.

6.9.3 Demographic Data

Demographic data (including age, gender, socio-economic status, performance status, co-morbidity, social support, stage of colorectal cancer and whether treatment was received via intravenous cannula or Hickman line) were collected on patients at the time that they consented to participate in the study (as shown in Table 6.2) (see Appendix 5). This was important since this information was used for describing the characteristics of the sample and was useful in the quantitative analysis, discussed in Chapter 10, for analysing whether there were any group by time interactions between changes in self care, control and self efficacy and patients' demographics. In particular, stage of disease was used in the analysis since the literature (reviewed in Chapter 4) led the researcher to consider that stage of disease may influence patients' perceptions of control in particular, and was helpful for determining whether stage of disease influenced the degree of self care carried out by patients and their perceptions of self efficacy (group by time interaction).

6.9.4 Qualitative Semi-Structured Interviews

A convenience sub sample of patients (n=10) who had consented to participate in the full study, were invited to take part in the qualitative semi structured interviews conducted on two occasions at the beginning (at the start of cycle 1/month 1) and end (at the end of cycle 6/month 6) of their six month course of chemotherapy treatment (as shown in Table 6.2). The beginning of patients' treatment (start of cycle 1) was chosen as the time point for the first interview as this provided the opportunity to explore patients' perceptions and experiences of control, self efficacy and their perception towards becoming involved in self care at the beginning of their chemotherapy treatment. The end of treatment (end of cycle 6) was chosen as the time point for the second interview as this provided the opportunity to explore these perceptions again and to identify if these and patients' perceptions and experiences of their subsequent involvement in self care had changed and whether they had influenced their involvement in self care throughout the course of their chemotherapy treatment. As acknowledged earlier, the researcher did not conduct qualitative interviews with patients in the middle of their treatment, as was done so with the quantitative data collection, since it was considered that in the second interview at the end of patients' treatment, patients would be able to discuss their experiences during their full course of treatment over the previous six months.

6.9.5 Quantitative Questionnaires and Diaries

Patients were asked to complete a questionnaire booklet (containing 2 questionnaires; the Illness Perception Questionnaire (revised) (Moss Morris et al, 2002) and the Strategies Used by People to Promote Health (Lev and Owen, 1996)) (shown in Appendix 3) and a self care diary (example of a page of the daily diary is shown in Appendix 4) on three occasions: at the start (cycle 1/month 1), middle (cycle 3/month 3) and end of their treatment (cycle 6/month 6) (as shown in Table 2). Patients were asked to complete the questionnaires at the beginning of cycles 1, 3 and 6 and were asked to complete the self care diary for the duration of their first, third and sixth cycles of treatment (1 month each) in

order to collect and analyse patients' daily self care actions during that month. This was important for obtaining an accurate account of the degree of self care and the types of self care activities carried out by patients at the beginning, middle and end of their treatment. The rationales for the choice of the particular instruments that were used in the study and their associated reliability and validity are reported in sections 6.9.9, 6.9.10 and 6.9.11.

Three time points were chosen for measuring changes over time, since in quantitative, longitudinal data collection, three data collection points are considered to be an appropriate number of waves, whereas two data collection points are inadequate for studying patterns of change (Singer and Willet, 1996). These specific time points (cycles 1, 3 and 6) were chosen within the context of this study since they provided an opportunity to quantify, and correlate, any changes, and associations between, patients' degree of involvement in self care, and their perceptions of control and self-efficacy at the beginning, mid-point, and end of their treatment, and hence, allowed the researcher to observe any changes in the quantitative measurement of the variables across the duration of patients' treatment.

| Instrument | Cycle 1 (Month 1) | Cycle 2 (Month 2) | Cycle 3 (Month 3) | Cycle 4 (Month 4) | Cycle 5 (Month 5) | Cycle 6 (Month 6) |
|--|----------------------|----------------------|----------------------|----------------------|----------------------|----------------------|
| Demographic record form | ✓ | | | | | |
| Semi-structured interview | ✓ | | | | | ✓ |
| Self care diary | ✓ | | ✓ | | | ✓ |
| Questionnaire booklet (containing IPQ-R and SUPPH) | ✓ | | ✓ | | | ✓ |

Table 6.2: Data collection time points

6.9.6 Methods and Instruments of Data Collection

Qualitative semi-structured interviews, and quantitative questionnaires and self care diaries were used in this study to explore patients' perceptions and experiences of being involved in self care, and their perceptions of control and self efficacy during chemotherapy

treatment for colorectal cancer. Table 6.3 demonstrates how these methods and instruments were used to answer the research questions in the study. The following discussion considers the rationale for each method or instrument that was used in the study, supported by a consideration of relevant literature.

| Research Question | Method/Instrument |
|---|--|
| 1. How do patients describe the meaning of self care and their involvement in self care and what are their perceptions of control and self-efficacy between the beginning and end of their course of chemotherapy treatment for cancer? | Semi-structured interview |
| 2. Does patients' degree of involvement in self care, and perceptions of control and self-efficacy change between the beginning, middle and end of their course of chemotherapy treatment? | Questionnaires: - Illness Perception Questionnaire (revised) - Strategies Used by People to Promote Health Self Care Diary |
| 3. Is patients' degree of involvement in self care associated with their perceptions of control and self efficacy at the beginning, middle and end of their course of chemotherapy treatment? | Semi-structured interview Questionnaires: - Illness Perception Questionnaire (revised) - Strategies Used by People to Promote Health Self Care Diary |

Table 6.3: Research questions and methods/instruments

6.9.7 Demographic Data

Demographic data were collected from each patient using the demographic record sheet (Appendix 5). Information on patients' age, gender, socio-economic status, performance status, co-morbidity, social support, stage of colorectal cancer and whether treatment was received via intravenous cannula or Hickman line, were collected. As noted in section 6.9.3, this information was important since it was used for describing the characteristics of the sample and was useful in the quantitative analysis, discussed in Chapter 10, for analysing whether there were any group by time interactions between changes in self care, control and patients' stage of disease.

6.9.8 Qualitative Semi-Structured Interviews

Semi-structured interviews were used in this study to provide a rich understanding of patients' perceptions and experiences of their involvement in self care, the meanings that they ascribed to their self care, and their perceptions of control and self efficacy. Interviews are one of the most popular methods used in qualitative designs (Robson, 2002), although their purpose varies in accordance with the context of the study in which they are being used. For example, interviews may be used in a qualitative study to explore the meaning of a particular phenomenon from participants' perspectives, or can be used as part of a qualitative component in a mixed method study, as discussed in section 6.5.1, for complementarity and expansion purposes in using qualitative findings to enhance and elaborate and expand upon quantitative findings, expanding the breadth and depth of an investigation of a particular phenomenon (Greene et al, 1989; Brannen, 2005).

Interviews are particularly useful for encouraging participants to talk freely about the topics of interest in a study (Polit and Hungler, 1998) and are a valuable adjunct to the use of questionnaires since they can illuminate and expand upon patients' somewhat standardised and superficial (by nature of the closed ended questions in quantitative methods and the lack of opportunity to provide further detail) responses in quantitative methods (Polit and Hungler, 1998). Furthermore, interviews not only enable a more in-depth discussion of the issues of interest in a study, but also allow the researcher to observe the participants' body language, level of understanding and degree of cooperativeness, all of which are useful features in facilitating interpretation of the data (Polit and Hungler, 1998; Robson, 2002).

The discussion in Chapter 5 revealed that qualitative interviews are a particularly valuable vehicle for articulating the uniqueness and individuality of participants' perceptions and experiences (Dill et al, 1995). In particular, they have been found to provide an in depth insight into the meanings that patients ascribe to self care (Dill et al, 1995; Plach et al, 2005) and their rationales for involvement, or non involvement, in self care (Sims, 1999;

Riegel and Carlson, 2002; Horowitz et al, 2004) and also their perceptions of control (Bulsara et al, 2004; Link et al, 2004). As also noted in Chapter 5, however, further research of this nature is required amongst patients with cancer in order to determine the uniqueness of patients' perceptions and experiences of their involvement in self care, and the influence of their perceptions of control and self efficacy.

Furthermore, Dill et al (1995) call for an alternative perspective of the significance of self care to individual patients, which can only be achieved using a different methodological approach to the ones used previously. Rather than using purely quantitative, positivist methodologies, which often standardise patients' responses and curtail the ability to extract the patients' perceptions and meanings (Dill et al, 1995) of their involvement in self care and the influence of their perceptions of control and self efficacy, the combination of using qualitative, interpretive methodologies can help to focus on the individual and unique meanings and perceptions of patients' involvement in self care (Dill et al, 1995).

Hence, the researcher considered the use of qualitative semi-structured interviews to be consistent with the patient-focussed approach adopted in this study, as detailed in Chapter 5, and would complement the quantitative findings in terms of offering an understanding of how patients made sense of their involvement in self care, and changes in their involvement in self care, and the importance of their perceptions of control and self efficacy and how these influenced their self care behaviours. The researcher also intended that using a mixed method approach would be valuable for highlighting the contribution that both qualitative and quantitative approaches, when integrated, made towards the evidence base in terms of offering a greater understanding of patients' perceptions and experiences of being involved in self care, and their perceptions of control and self efficacy during their six month course of chemotherapy treatment, than using one approach alone.

6.9.8.1 The Interview Guide

The content of discussion in a semi-structured interview is guided by a list of topics or questions that the researcher wishes to discuss with participants, yet, flexibility is permitted in the sequencing or wording of questions, or the time devoted to each topic of discussion (Robson, 2002). This is in comparison to structured interviews in which the process of carrying out the interview, for example, sequencing and wording of questions, must be identical for all participants, or unstructured interviews, which are guided by a very broad, loose interview guide and which are structured in a way that is comparable to an in-depth, lengthy conversation between the researcher and participant (Robson, 2002).

Two interviews were conducted with each participant in the sub sample of patients who consented to participate in the interviews. Both interview guides which were used in the interviews conducted at the beginning (cycle 1) and end of patients' treatment (cycle 6) were broadly guided by Leventhal's Self Regulation Model (see Appendices 6 and 7) but differed slightly given the timing of each interview and given the purpose of the interviews in relation to the aim and research questions of the study. In particular, the aim of the study was to explore patients' perceptions and experiences of being involved in self care and perceptions of control and self-efficacy over time amongst patients receiving a six month course of chemotherapy treatment for colorectal cancer. Hence, the interview guide used in the conduct of the second set of interviews which were conducted at the end of patients' treatment, was also based on patients' responses in their first interview and their responses in the quantitative questionnaires and diaries. This was important to allow the researcher to explore whether patients perceived their meanings of, and their involvement in, self care and their perceptions of control and self efficacy to have changed between the beginning and end of their six month course of chemotherapy treatment and to allow the researcher to probe for explanations behind such changes.

As noted, both the first and second sets of interviews were guided by relevant components of Leventhal's Self Regulation Model (including consequences, emotional representations, and personal and treatment control). In the following discussion the particular components of the model to which the questions related are noted in brackets. All interviews began with an explanation of the purpose of the interview and the topics that would be discussed during the interview and asked patients to start off by giving an account of how they had been coping with recent events (for example, in the first interview, this referred to the period surrounding diagnosis and starting treatment, and in the second interview, this referred to their course of treatment over the preceding six months). Hence, in the first interview (beginning of treatment), this was important for helping to capture patients' perceptions and experiences of the events leading up to and receiving their diagnosis, and their thoughts about starting chemotherapy treatment and their perceptions of the treatment-related side effects that they may experience (relating to the 'consequences' and 'emotional representations' components of the model). In the second interview (end of treatment), this question captured patients' perceptions and experiences of coping with their chemotherapy treatment and the impact that this had had on them and their lives (relating to the 'consequences' and 'emotional representations' components of the model). These opening questions also allowed patients to discuss issues around their plans for the future both during and following the end of their treatment and their coping styles, as these issues may have shaped their perceptions towards their involvement in self care.

In relation to perceptions and experiences of control and self efficacy, patients were asked in both interviews how much control they felt they had over their treatment and in carrying out self care, and how confident they felt about this (relating to 'personal' and 'treatment control'). This was important for exploring patients' perceptions and experiences of taking control and feeling confident during their treatment, and the influence of this on their perceptions towards, and experiences of, being involved in self care during their course of treatment. In relation to self care, patients were asked to discuss the importance of being

involved in their self care and the self care activities that they were aware of and had employed both at the start (cycle 1 interview) and end of treatment (cycle 6 interviews) as well as their rationales for choosing these. These questions were important for exploring how patients understand self care and the perceived value of their involvement in their self care during the course of their treatment. Patients were also asked how much information they had been given about how to carry out self care and where they found additional information on self care from other sources, which was important for identifying how they obtained self care information, since these issues may have shaped their perceptions, and experiences, of being involved in self care.

6.9.8.2 Quality of the Qualitative Data

The main challenge in conducting qualitative interviews perhaps refers to the assurance that the researcher can guarantee that the findings are of a high quality and limit the potential for bias within the research process and its subsequent findings. It has been argued that qualitative research findings should be tested for credibility or accuracy using terms and criteria that have been developed exclusively for this approach, as opposed to the traditional criteria used to judge quantitative studies (Parahoo, 1997; Cutcliffe and McKenna, 1999) however, exactly what the criteria for judging the quality of qualitative research constitutes has been the subject of much debate (Hammersely, 1992; Sandelowski, 1993; Guba and Lincoln, 1994; Whitemore et al, 2001; Tobin and Begley, 2004). What can be gleaned from this debate, however, are several pragmatic requirements for ensuring that the findings from qualitative research are of a high quality. This includes ensuring that the research findings are clearly derived from the data and not the researcher's own assumptions; that the findings are an accurate interpretation of participants' perceptions or experiences, illustrated by the use of appropriate quotes or examples and verification of the findings; are transferable and relevant, for example, to other populations who carry out self care; and that the interview process, from which the findings originated, is clearly documented and justified and hence, provides an 'audit trail' (Guba and Lincoln, 1994; Whitemore et al,

2001; Bryman, 2004; Tobin and Begley, 2004). Several strategies, detailed below, were used by the researcher to meet these requirements in the current study.

Since the quality of the interview findings are often related to the role and proficiency of the researcher (Parahoo, 1997; Polit and Hungler, 1998), the researcher employed several strategies in an attempt to ensure that the findings from the qualitative interviews were of a high quality. During the interview process, all interviews were tape recorded and detailed fieldnotes to accompany each interview were made by the researcher, as recommended by Robson (2002). The researcher was also conscious to ensure that the transcripts contained notes of participants' pauses in conversation and body language to aid interpretation of the analysis. The transcripts were read several times alongside listening to the tape recordings to check for any errors, which helped to ensure reliability of the transcripts (Robson, 2002).

Although face to face interviews have been widely recommended as a method for seeking new insights into a phenomenon from participants' perspectives (Robson, 2002), allowing the researcher to probe participants' responses for further detail or clarification, the very nature of this can contribute a degree of bias within the study (Robson, 2002). This is because the researcher may lead participants towards responses which they may not have previously considered or simply voice because they perceive this to be what the researcher wants to hear (Robson, 2002). This is considered in further detail with reference to the current study in section 6.10.

The researcher was careful to follow the interview guide as much as possible in each interview and was careful to minimise the degree to which patients may have been led towards a particular response. In doing so, the researcher attempted 'neutral' probing, which as clarified by Polit and Hungler (2002), are probes which are less likely to influence the content of the participants' response. Examples of this kind of probing, included "how do you feel about that", "can you tell me more" and "why do you think that." The pilot

study in particular, highlighted the importance to the researcher of reviewing the transcripts following each interview to reflect on, and learn from her interview technique.

In relation to the analysis of interviews, detailed records of how codes and themes emerged from the data were made (Robson, 2002). The researcher also enlisted the help of an experienced colleague, both of whom performed independent coding on a random selection of transcripts, as recommended by Appleton (1995). The codes were then compared to determine the level of agreement between both researchers in an attempt to confirm that these findings were derived from the data itself. Other strategies, recommended in the literature and carried out by the researcher included, verifying the findings from the first set of interviews with participants (Guba and Lincoln, 1994; Miles and Huberman, 1994; Nolan and Behi, 1995) in order to confirm that the findings accurately represent what the participants have said and to limit the potential for research bias in simply accepting their own interpretation of the data. The findings from the second set of interviews were not verified, which the researcher acknowledged in Chapter 12, as a limitation of the study. Another strategy used for limiting researcher bias, was conscious reflection of the researcher's role within the research and the impact that this had had on the processes of data collection and analysis. There is further discussion of this in section 6.10.

The following discussion considers the use of the quantitative methods in measuring changes in patients' perceptions and experiences of their involvement in self care, and of their perceptions of control and self efficacy, during the course of their treatment, and the rationales for why these particular methods were chosen.

6.9.9 Assessment of Perceived Control

Chapter 4 identified that the field of research on perceived control is peppered with challenges stemming from the lack of theoretical and empirical clarity of the construct of control, and the use of its' related and synonymous terms (Thompson and Spacapan, 1991;

Skinner, 1996; Walker, 2001). It is not surprising, therefore, that there have been a number of different instruments which have been developed to measure the construct of control and its' related terms. Since these instruments differ with respect to the specific conceptualisation of control that they are intended to measure, some are more relevant to some research studies than others. Pragmatically, this has made it difficult for researchers to determine the constructs of control that are most relevant to their study, and consequently decide upon the most appropriate instruments for measuring these constructs (Skinner, 1996). Two of the most common instruments for measuring perceived control and its related constructs have included, the Multidimensional Health Locus of Control (MHLC) Scales (Wallston et al, 1978; 1994), and the Illness Perception Questionnaire (Weinman et al, 1996; Moss Morris et al, 2002).

The Multidimensional Health Locus of Control (MHLC) scale has been used since the 1970's and is a popular instrument for measuring locus of control. As such, the MHLC has been used in hundreds of studies throughout the world, including studies in patients with cancer (Barroso et al, 2000; Mohamed et al, 2005; Naus et al, 2005). The MHLC was developed in the USA by Wallston and colleagues (1978, 1994) and is based on Rotter's (1954) social learning theory. The MHLC consists of three different forms intended to be used independently: Forms A and B are general scales, and the more recently introduced Form C, is designed to be condition-specific and completed by people with a particular condition (Wallston, 2005). Wallston (2005) reported that whilst forms A and B measure beliefs about control of one's health status, form C measures beliefs about control of one's illness or disease. Each form has three six-item subscales to measure three aspects of control: internality, powerful others externality, and chance externality (form C contains two dimensions, 'doctors' and 'other people' within the powerful others dimension). All three forms of the MHLC have established validity and reliability (Wallston et al, 1978, 1994, 2005), however, Wallston (2005) identified that most studies that have attempted to correlate MHLC scores with measures of health behaviour have not provided strong

evidence of an association between any of the three MHLC subscales (particularly the internality dimension) and behaviour.

Luszczynska and Schwarzer (2005) claim that for the purposes of predicting behaviours, constructs such as the more narrowly defined, perceived behavioural control (Ajzen, 1991; Moss Morris et al, 2002), or self efficacy (Bandura, 1997) are more useful, as also noted by Armitage (2003). Measures of perceived control, as opposed to locus of control, for example, were noted by Thompson and Collins (1995) to provide more accurate predictions of psychological adjustment. One such questionnaire which measures the construct of perceived control, amongst other illness perceptions, is the Illness Perception Questionnaire (IPQ) (Weinman et al, 1996), and its recent revision, the Illness Perception Questionnaire (IPQ-R) (revised) (Moss Morris et al, 2002). The Illness Perception Questionnaire (revised) (Moss Morris et al, 2002) was chosen as the instrument to measure perceived control in the current study. The following section considers the relevance of this questionnaire to the current study and the rationales for its choice.

6.9.9.1 The Illness Perception Questionnaire (revised)

The Illness Perception Questionnaire (revised) (IPQ-R) (Moss Morris et al, 2002) is based on Leventhal's Self Regulation Model (Leventhal et al, 1984, 1997, 2001), and was developed to provide a quantitative measurement of the five components of Leventhal's model (identify, cause, timeline, consequences and control/cure). The IPQ-R contains nine subscales to measure these components and, similar to the original IPQ (Weinman et al, 1996), is easy for patients to complete, requiring them to circle or tick a box to indicate their response. Furthermore, its items can be tailored to specific populations (Weinman et al, 1996; Moss Morris et al, 2002). Items on the questionnaire are coded so that high scores represent strong beliefs on a particular dimension. Accordingly, high scores on the control dimensions reflect more positive beliefs about how well patients feel they understand and can control the effects of their illness (Moss Morris et al, 2002).

Both the IPQ and IPQ-R are popular instruments and have been used extensively throughout the world, to measure patients' illness perceptions, including their perceptions of personal control, including, New Zealand and the UK (Moss Morris et al, 2002) . This has enhanced the consistency of findings of research on patients' perceptions of illness and, as the following discussion reveals, has led to the development of a large evidence base on the use of this instrument (Petrie et al, 1996; Buick, 1997; Griva et al, 2000; Horne and Weinman, 2002; Moss Morris et al, 2002; Jopson and Moss Morris, 2003; Llewellyn et al, 2003; Whitmarsh et al, 2003; Carlisle et al, 2005; Hagger and Orbell, 2005).

The original IPQ was modified to create the revised version, the IPQ-R, by Moss Morris et al (2002) who, in response to feedback from researchers regarding some variation in the internal consistency of some of the subscales, amended the original subscales and added new subscales (to create nine in total rather than the original five). Research using the IPQ and IPQ-R has focussed on a variety of patient groups including patients with heart disease (Petrie et al., 1996), patients recovering from a myocardial infarction (Petrie et al, 1996; Moss Morris et al, 2002; Whitmarsh et al, 2003; MacInnes, 2006), as well as patients with cancer (Buick, 1997). Both questionnaires have also demonstrated good predictive ability in determining those patients who will adhere to treatment recommendations (Horne & Weinman, 2002), those who will attend rehabilitation programmes (Whitmarsh et al, 2003), and those who will adhere to cancer screening programmes (Hagger and Orbell, 2005). International studies in patients with arthritis, diabetes, asthma, HIV/AIDS, following myocardial infarction (Moss Morris et al, 2002), and multiple sclerosis (Jopson and Moss Morris, 2003) and in patients undergoing cervical screening (Hagger and Orbell, 2005), have confirmed that the IPQ-R has retained a reasonable level of reliability and validity. Cronbach's alpha coefficients were reported by Moss Morris et al (2002) for all dimensions, including, personal and treatment control, which were noted to be 0.81 and 0.80, respectively. Test-retest reliability over a 3 week period was also reported by Moss Morris et al (2002) as having good stability with correlations ranging from 0.46 to 0.88. Six-month

test-retest reliability confirmed that the IPQ-R had acceptable consistency when compared with the 3 week test-retest data (Moss Morris et al, 2002).

In summary, the ability of the IPQ-R to measure patients' perceptions of control, the ability of the questionnaire to predict health behaviours, its widespread use and ease of completion, makes this questionnaire suitable for the current study. The particular subscales of interest in the current study were: personal control, treatment control, consequences, and emotional representations, since these were considered by the researcher to be most relevant to patients' perceptions of control and their self care. The results of initial testing of a shortened version of the IPQ/IPQ-R, the Brief Illness Perception Questionnaire, have recently been published (Broadbent et al, 2006) however, this information was not available at the time of the start of the current study.

6.9.10 Assessment of Self Efficacy

Self-efficacy has been widely measured in relation to health and health behaviour change. However, as the following discussion reveals, its measurement has been confusing, inconsistent and ad hoc. For example, some self-efficacy scales have been developed as a generalised measure of self-efficacy, however, Bandura (1997) proposes that self-efficacy should be measured in relation to the specific task to be performed or context in which the task is to be performed. He argues that generalised measures of self efficacy decontextualise the nature of self efficacy, conceptualising it into a generalised personality trait, rather than a task or context-specific judgement of one's belief or confidence to perform a particular behaviour (Bandura, 1997). As a result, these scales lack specificity and sensitivity (Bandura, 1997).

Conversely, there are many other scales which have been developed specifically related to a particular task or context, or for use within a particular study or population. Examples of these kinds of scales include; the Self Efficacy for Exercise Scale (Resnick and Jenkins,

2000), the Breastfeeding Self Efficacy Scale (Creedy et al, 2003), the Arthritis Self Efficacy Scale (Lorig and Holman, 1998), and the Diabetes Specific Confidence in Diabetes Self Care Scale (Van der Ven et al, 2003). Paradoxically, however, because of the specificity of these scales, they have received limited testing and hence, have done little in consolidating the consistent measurement of self-efficacy. Despite this, self-efficacy scales which have been designed for a specific context or population are believed to provide a truer picture of one's self-efficacy perceptions, than a generalised measure (Bandura, 1997).

Given the importance of choosing a self efficacy measure that was specific to the research context, the researcher was keen to identify an instrument which had been specifically designed to measure the self-efficacy perceptions of patients with cancer. Several scales designed for use in patients with cancer have been developed including the Stanford Inventory of Cancer Patient Adjustment (SICPA) (Telch and Telch, 1982), the Cancer Behaviour Inventory (CBI) (Merluzzi and Martinez Sanchez, 1997a, 2001), the Communication and Attitudinal Self Efficacy Scale for Cancer (CASE-cancer) (Wolf et al, 2005), and the Strategies Used by People to Promote Health (SUPPH) (Lev and Owen, 1996).

The Stanford Inventory of Cancer Patient Adjustment (SICPA) is a 38-item scale designed to assess patients' beliefs about their ability to cope with their cancer (Telch and Telch, 1982). Six domains are covered in the questionnaire including coping with medical procedures, communication with physicians, friends and family, participation in vocational, social and physical activities, personal management, affective management and self satisfaction. However, although the scale was devised by the authors some years ago now (in 1982) for use in patients with cancer, information relating to the development and initial psychometric properties of the scale has never been published. Instead, information about the scale can be gleaned from only four published papers on studies which have utilised the scale (Telch and Telch, 1986; Cunningham et al, 1991; D'Errico et al, 1999; Weber et al,

2004). These studies reported on some psychometric properties of the scale and identified its use in patients with different cancers (Telch and Telch, 1986; Cunningham et al, 1991; Weber et al, 2004), however, it may be fair to say that since only four published reports of the scale are available, the scale has been subject to a minimal degree of testing. Furthermore, the scale focuses on self-efficacy in relation to coping with cancer and improving quality of life rather than specifically relating to patients' perceptions of their self-efficacy in performing self-care.

Another measure of self-efficacy in coping with cancer, the Cancer Behaviour Inventory (CBI) (Merluzzi and Martinez Sanchez 1997a; Merluzzi et al, 2001), was designed to assess the expectations of how patients with cancer would cope with a particular problem. The 33-item questionnaire measures seven dimensions of coping with cancer: maintenance of activity and independence, seeking and understanding medical information, stress management, coping with treatment-related side effects, accepting cancer/maintaining a positive attitude, affective regulation, and seeking social support. The scale was designed to be used in patients with different types of cancer, including patients with breast, lung, prostate and colorectal cancers (Merluzzi and Martinez Sanchez 1997a, 1997b; Merluzzi et al, 2001). The scale is useful since it provides a profile of patients' strengths and weaknesses in relation to their expectations for coping with the effects of their cancer, allowing health professionals' interventions to be tailored towards these expectations (Merluzzi et al, 2001). However, development of the scale has been fairly recent and although initial testing has found the scale to be both reliable and valid, and clinically relevant (Merluzzi and Martinez Sanchez 1997a, 1997b; Merluzzi et al, 2001), further testing is warranted, particularly in diverse groups of patients with cancer (Merluzzi and Martinez Sanchez 1997a). Furthermore, similar to the SICPA, this scale focuses on self efficacy in relation to coping with cancer rather than specifically, patients' self care behaviour.

Another scale which has been recently developed is the Communication and Attitudinal Self Efficacy Scale for Cancer (CASE-cancer) (Wolf et al, 2005). This scale has been developed to measure self efficacy within the context of communication and positive attitude for patients with cancer. This instrument was not available at the start of the current study, however, it would also not have been the most appropriate choice of instrument since it does not focus on measuring patients' self efficacy to perform self care behaviours. Furthermore, owing to its recent development, information on its psychometric properties is limited.

One scale was identified which focussed on measuring patients' perceptions of self efficacy in relation to performing self care behaviours, hence this seemed to be the most appropriate choice of instrument for use in the current study. This scale, the Strategies Used by People to Promote Health (SUPPH) (Lev and Owen, 1996) is a 29-item, self report questionnaire, which is brief and easily administered. The relevance of the SUPPH to the current study and the rationales for its choice is considered in the following section.

6.9.10.1 The Strategies Used by People to Promote Health

The Strategies Used by People to Promote Health (SUPPH) covers three domains related to self efficacy and self care: positive attitudes, stress reduction, making decisions; and asks patients to rate the degree of confidence that he or she has in carrying out behaviours identified in each of the items within these domains on a 5-point scale (1=very little confidence to 5=very confident). The instrument is scored by summing the responses, for each subscale. Higher scores indicate a greater degree of confidence for a particular behaviour. The scale is easy for patients to use, requiring them to circle or tick a box to indicate their response and it is not too lengthy to complete.

The scale has previously been tested in patients with cancer (Lev and Owen, 1996; Lev et al, 1999; Lev et al, 2001; Lev et al, 2004; Eller et al, 2006) and has been found to be

satisfactory in relation to its validity and reliability in measuring patients' self efficacy to perform self care (Lev and Owen, 1996; Lev et al, 1999; Lev et al, 2001; Lev et al, 2004; Eller et al, 2006). An internal consistency reliability of between 0.93 and 0.95 has been reported and criterion validity of the SUPPH has been initially established by the developers (Lev and Owen, 1996). Further testing of the instrument in patients with end stage renal disease (Lev and Owen, 1996; Tsay and Hung, 2004), chronic back pain (Nyiendo et al., 2001) and in patients recovering from stroke (Robinson Smith et al, 2000; Robinson Smith and Allen, 2002) have provided support for its reliability, validity and relevance to wider patient groups.

In summary, the very nature of the SUPPH in being the only scale to assess self-efficacy in relation to self-care, its previous use in patients with cancer (Lev and Owen, 1996; Lev et al, 1999; Lev et al, 2001; Lev et al, 2004; Eller et al, 2006) and its reported validity and reliability combined with its wide applicability, and ease of completion suggested that this instrument was the most suitable for this study.

6.9.11 Assessment of Self Care

Chapter 3 highlighted that the evidence base on self care has been weakened by the lack of consistency in the nature of instruments used to evaluate patients' patterns of involvement in self care and the reliability and validity of existing self care behaviour questionnaires. Two principal approaches to measuring self care have been identified in previous research on patients' patterns of involvement in self care. These have included questionnaires and diaries.

Questionnaires, for example, the Effectiveness of Self Care Questionnaire (ESCQ) (Craddock et al, 1993) and Dodd's self care behaviour questionnaire (Dodd, 1982) have been cited in the literature. The decision to use a questionnaire to measure self care, however, has rarely been justified in the literature, and questionnaires, such as those cited

here, have been used infrequently amongst existing research. Subsequently, concerns remain over their limited testing and validation. In exemplifying these concerns, an account by Craddock et al (1993) highlights that their Effectiveness of Self Care Questionnaire was modified from Nail et al's self care diary yet no rationale for this modification is given. Furthermore, this questionnaire does not appear to have been used in any further studies. This may have been because the authors reported that the instrument may not have been sensitive to detect changes in the performance and effectiveness of self care behaviours (Craddock et al, 1993).

Dodd (1984) also acknowledged some years ago that questionnaires are typically designed to measure patients' involvement in self care at one single point in time and thus, they do not adequately reflect changes in patients' involvement in self care over time. Furthermore, the questionnaire approach often relies on patients having to recall their self care activities, sometimes a number of weeks after the event. Thus, the ability of a questionnaire to provide an accurate account of patients' patterns of involvement in self care is questionable.

Another approach, the diary, has been claimed to satisfy many of the concerns raised by the use of self care questionnaires and, as such, has been widely used in studies of patients' symptoms and patterns of involvement in self care (Dodd, 1987, 1988; Nail et al, 1991; Foltz et al, 1996; Richardson and Ream, 1997; Schumacher et al, 2002; Miaskowski et al, 2004; Williams and Schreier, 2004; Ream et al, 2006). The diary approach is believed to accurately measure patients' patterns of involvement in self care since it does not rely so heavily on patient recall and allows individuals to document events related to their self care at regular intervals, as close to the time of the event as possible (Rakowski, et al, 1988; Richardson, 1994; Richardson and Ream, 1997; Ream, 2002). The reliability, validity, feasibility and sensitivity of diaries to accurately reflect patients' patterns of involvement in self care (Geddes et al, 1990; Oleske et al, 1990; Richardson and Ream, 1997; Ream, 2002) made the self care diary an appropriate choice of method for assessing patients'

involvement in self care in this study, and how this changes throughout their course of chemotherapy treatment. The following section discusses the structure of the self care diary in this study and the rationale for this.

6.9.11.1 Structure of the Self Care Diary

Although diaries have been used in previous studies of self care in patients with cancer (Dodd, 1987, 1988; Nail et al, 1991; Foltz et al, 1996; Richardson and Ream, 1997; Schumacher et al, 2002; Miaskowski et al, 2004; Williams and Schreier, 2004; Andersen et al, 2006; Ream et al, 2006), there were no existing diaries identified within the literature which would have been entirely suitable for the aim of the current study. Therefore, a semi-structured self care diary, drawing on the work of previous research (for example, Nail et al, 1991; Foltz et al, 1996; Richardson and Ream, 1997; and Ream, 2002 (and Ream et al, 2006)) was developed for this study (an example of a page from the diary is shown in Appendix 4). Several previous researchers have favoured diaries with a structured approach since they found that this enhanced the accuracy and completeness of the self care information provided by patients (Nail et al, 1991; Foltz et al, 1996 and Richardson and Ream, 1997; Ream, 2002). Since the purpose of the diary was to quantify patients' involvement in self care at three time points over the course of their chemotherapy treatment, a more structured approach seemed sensible and, therefore, the diary entailed mainly closed ended questions.

The diary contained a checklist of side effects commonly experienced by patients receiving the Mayo regimen for colorectal cancer and a list of self-care activities commonly aimed at managing these side effects. It was developed from the existing literature and validated by the Consultant at the clinical site where the research was being conducted, who reviewed the content of the diary for relevance and appropriateness. Patients were asked to complete the diary daily for a full cycle of treatment (approximately 30 days) and to tick a box to indicate the side effects that they had experienced and the self care activities that they had

carried out. Patients were also asked to answer yes or no to a question about whether they felt confident to carry out self care and also to whether they had carried out self care to prevent side effects from occurring, or to relieve side effects once they had occurred. These questions were designed with the purpose of being correlated with patients' responses in the questionnaires, and from their descriptions in the qualitative semi-structured interviews.

The structured format of the diaries was also important to aid the analysis of the diary data and to help limit the amount of complex and potentially unwieldy data obtained from the diary since this is a common concern in diary-based studies (Richardson and Ream, 1997; Andersen et al, 2006). The time and energy demands required by patients during the completion of diaries (Faithful, 1992; Richardson, 1994) and the potential for missing information (Richardson, 1994; Ream, 2002) have also been recognised as limitations of the diary approach (in Chapter 12) and may have been a source of bias in the study, which is considered further in section 6.10. Hence, the layout and content of the diary were kept simple and consistent in order to prevent confusion and promote ease and consistency of completion for patients. Clear instructions on how to complete the diary were also given verbally by the researcher when the patient was recruited to the study. Analysis of diary data is often considered to be unwieldy due to the large amount of data that it produces. This was important to consider in the current study and the method of analysis is discussed in Chapter 10.

6.9.12 Managing Data Collection

In managing the process of data collection during the study, several issues were important. It was essential that all patients participating in the study did not feel overburdened or confused by what they were asked to do. Hence, the researcher attempted to minimise these effects by ensuring that all instructions and data collection tools were kept simple, practical and not too long in their completion so as to curtail respondent confusion and burden. Recruitment rates were monitored on a monthly basis and records as to when patients were

due to attend the clinic for further treatment or when they were due to finish their treatment, were accurately maintained throughout the study. This was important for ensuring that the interviews were conducted with patients and questionnaires and diaries completed at the designated time points. The reasons why patients refused to participate in the study, or indeed withdrew from the study, were recorded where possible, as this was important for ascertaining the accuracy and relevance of the study findings and for helping to inform the design of future research.

6.10 Potential for Bias

Confidence in the validity of study findings is increased where there is evidence of researcher sensitivity to the ways in which the data may have been shaped by the researcher and their presence (Murphy et al, 1998). Thus, in this section, the researcher acknowledged the sources of potential bias in the current study relating to the design of the research and the role of the researcher. In particular, the longitudinal nature of the study, and the presence of the researcher at the weekly colorectal cancer clinic, meant that the researcher had repeated contact with patients throughout the duration of the study. Whilst, on the one hand this was integral to the study design and valuable for developing a good relationship with patients and ensuring that few eligible patients were missed, this may have influenced patients' responses and motivation to participate in the study. Hence, this could have been a threat to objectivity and hence, the validity of the study.

In following ethical and management approval, recruitment had to be conducted via clinical staff at the clinical site. Whilst, this was important in one respect for helping to ensure that fewer patients were missed, it also raised the possibility of "gatekeeping", where patients may have been subject to biased selection from clinical staff. For example, those patients who they deemed to be too anxious or unfit to participate, may have been excluded by clinical staff from being identified as eligible to participate in the study. Gatekeeping by clinical staff has been noted in the literature as having the potential to slow or skew

recruitment and, therefore, affect the representativeness of the sample (Aitken et al, 2003) thus, it was important for the researcher to have ongoing dialogue with the clinical staff in order to minimise the risk of this.

The researcher is aware that by introducing the idea of self care to patients, their responses towards this may have been different to those with less awareness about self care. Ultimately, it may have in fact led them to think more about their self care and become more involved in their self care than they might have done. Furthermore, the conceptualisation of self care chosen to frame the study may have influenced patients' responses towards their self care. In particular, at the beginning of the study, self care was defined in terms of managing the physical effects of undergoing treatment, largely owing to the current literature and Musci and Dodd's (1990) definition of self care (as discussed in Chapter 3) which led the researcher to frame the study using this conceptualisation. This definition was used when the study was explained to patients, was used to structure the self care diary and was written on the front page of the diary, as requested by one patient during the pilot study. Hence, this may have led patients to view their self care predominantly in physical terms, rather than the wider emotional and social aspects of their self care. Chapters 9, 11 and 12 however, highlight the value of the qualitative interviews in being able to elicit patients' perceptions on the wider aspects of their self care.

Using a self care diary also increased the potential for missing data and increased the energy and time requirements of patients in completing it on a repeated basis (Faithful, 1992; Richardson, 1994; Ream, 2002). Richardson (1994) acknowledged that it is likely that patients' responses in the diary are dependent upon the patient's motivation, which subsequently may have led to a bias in reporting. Further bias was possible in relation to coding the questionnaires, diaries and interviews. Since the questionnaires and diaries were structured, this helped to minimise the level of bias that could affect these. However, the interviews could be considered as more subjective, and hence to ensure trustworthiness of

the thematic analysis, a random selection of transcripts were compared between the researcher and a colleague with experience in qualitative data analysis. This was important to ensure that there was a consistent level of agreement found between researchers on the themes originating from the data.

Finally, the interviews revealed on occasions that some patients may have been performing ineffective or inappropriate self care activities. The researcher acknowledged that it was important to remain objective and that she was unable to influence patients' behaviours by offering appropriate guidance in these instances, since this would be seen as an intervention. This, confronted with the desire to help patients, remained a source of tension for the researcher. Similar relating to role conflict between the researcher's role as a clinician and independent researcher have been reported in the literature (Johnson and MacLeod Clarke, 2003; Sterling and Peterson, 2005).

6.11 Data Analysis

The goals of data analysis were to provide a detailed understanding of how a mixed method approach contributed towards providing a broad, rich and in depth understanding of patients' perceptions and experiences of their involvement in self care and their perceptions of control and self efficacy during a six month course of chemotherapy treatment for colorectal cancer. It was at the stage of interpretation in which the qualitative and quantitative findings in this study were integrated in such a way that their findings were mutually illuminating. The qualitative and quantitative data sets for those patients who completed both of the qualitative semi structured interviews at the beginning and end of treatment and the quantitative data at all three time points at the beginning, middle and end of the study were integrated for the purpose of the merged analysis. These findings are discussed in Chapter 11.

The discussion in section 6.5.2 highlighted that integrating qualitative and quantitative findings is a particularly challenging issue for researchers (Sim and Sharp, 1998; Wendler, 2001; Bryman, 2007). In particular, the discussion revealed that this was because of the different epistemological and ontological perspectives inherent in each approach and the use of different data collection instruments (Sim and Sharp, 1998; Wendler, 2001; Bryman, 2007) and because of researchers' favouritism and familiarity with a particular approach or set of research findings which leads them to emphasis one over the other, rather than emphasising both in a mutually illuminating way (Bryman, 2007). Bryman (2007) also noted that there were few good practical examples within the literature on the most appropriate way for integrating qualitative and quantitative findings.

The researcher integrated the qualitative and quantitative findings in the current study following the guidance provided by Tashakkori and Teddlie (1998) and Onwuegbuzie and Teddlie (2003) since there was published evidence of their approaches to data analysis and integration and these seemed most relevant to the purposes for this mixed method study. Their guidance suggest that the analysis and interpretation of mixed method findings involves several stages; data analysis of the qualitative and quantitative data sets according to the principles of analysis pertinent to that type of data; data transformation, in which the quantitative data are converted into narrative data ('qualitised', Tashakkori and Teddlie, 1998) or in which the qualitative data are converted into numerical codes ('quantitised', Tashakkori and Teddlie, 1998); and, data integration, in which the separate data sets are combined into a coherent whole and can be used to search for logical patterns and meanings amongst both types of data (Tashakkori and Teddlie, 1998). The application of these stages in the current study is considered in the following sections.

6.11.1 Stage 1: Analysis of the Qualitative Semi Structured Interviews

Framework analysis was the method chosen in the current study for analysing the qualitative data (Pope et al, 2000; Green and Thorogood, 2004). Framework analysis

consists of five stages; familiarisation of the data; development of a thematic coding scheme; indexing, which involves applying the thematic coding scheme to the whole data set; charting, which provides a summary of perceptions and experiences according to the thematic framework so that they can be compared across and within interviews; and mapping and interpretation, where the charts are used to define concepts, map the range and nature of phenomena, and find associations between themes in order to provide explanations for the findings (Pope et al, 2000; Green and Thorogood, 2004). The application of these stages in the current study is considered below.

Stage 1: Familiarisation

All interviews in the current study were tape-recorded and transcribed verbatim. The tapes were listened to and transcripts re-read to allow the researcher to become completely familiar with the data. Rich, thick descriptions of patients' experiences and perceptions were also made for each patient to allow familiarisation of the data.

Stage 2: Development of thematic coding scheme

The thematic coding scheme was guided by the conceptualisation of self care used (Musci and Dodd, 1990) and the theoretical framework used in the study (Leventhal's Self Regulation Model) and also through a process of open coding which was conducted to identify the key themes within the data. For example, physical self care strategies used by patients was identified as a key theme as guided by the physical connotations of the conceptualisation of self care used in the study, whilst emotional self care strategies used by patients emerged from the data as a key self care strategy. The development of each of the themes identified in the qualitative data are discussed in further detail in Chapter 9.

The development of the thematic coding scheme was an iterative process in which the researcher moved back and forth between the coding scheme and the transcripts, continuously revising the coding scheme and re-coding the transcripts. Although the

researcher acknowledges that the use of qualitative computer software packages, such as N-Vivo, can be extremely useful in helping to manage data analysis, manual coding was used since this is “sufficient and speedier for small scale research projects” (Arksey and Knight, 1999, p163), and this allowed the researcher to easily compare the data and codes between the first and second set of interviews at a glance.

Stages 3 and 4: Indexing and charting

Once the final coding scheme had been applied to the whole data set, the researcher then developed a synopsis for each code which included its’ main themes and a summary of themes for each individual patient and allowed codes to be compared across and within each interview (see Appendices 8 and 9 for an example of each chart). The key themes generated from the qualitative data are noted and considered in detail in Chapter 9.

Stage 5: Mapping and interpretation

Finally, the tables and diagrams created in the previous stage were used to physically explore relationships between the codes, for example, between patients’ perceptions of control and their experiences of being involved in self care, and to provide explanations for the findings and to explore potential reasons for any deviant cases.

As well as independent coding by both the researcher and her colleague on a selection of transcripts, several other strategies were used to enhance the quality and credibility of the findings and reliability and validity of the analysis (as discussed in section 6.9.8.2), including the use of appropriate quotes to illustrate key themes and examples (as shown in Chapter 9), the use of frequency counts of key themes (as shown in Chapter 9), reporting on deviant cases and demonstrating explanations for these cases from within the data (as shown in Chapter 11), and comparing the themes identified in the study with those of other studies (considered in Chapter 12). The researcher also consciously reflected on the

potential for bias arising from her role as researcher within the study (as was discussed in section 6.10).

6.11.2 Stage 1: Analysis of the Quantitative Questionnaires and Diaries

The demographic data and the quantitative data from the questionnaires and diaries were entered into a quantitative software package, SPSS (Version, 13.0). Following this, the data set was 'cleaned' to check for errors and ensure the accuracy of the data set, in accordance with the guidance provided by Loewenthal (2001) (discussed in Chapter 8). The data were initially explored using descriptive statistics to provide frequencies (median and range) for the degree of patients' involvement in self care, and the types of self care activities that they carried out, and their perceptions of control and self-efficacy, and whether there were any changes in the mean scores between these variables for each of the three data collection points over the course of patients' treatment. This was useful for determining whether patients in the study reported higher or lower perceptions of control and self efficacy, and a higher or lower degree of involvement in self care over the course of their treatment.

The significance of changes in the study variables over time were determined through statistical analysis using non parametric Friedman's ANOVAs whilst associations between patients' perceptions of control and self efficacy with their degree of involvement in self care were predominantly analysed using non parametric Spearman's Rho association statistic (non parametric tests were used because of the ordinal nature of the variables).

6.11.3 Stage 2: Data Transformation

Following separate analyses of the qualitative and quantitative data sets, the quantitative data was converted into qualitative data, a process known as 'qualitising' (Tashakkori and Teddlie, 1998). In this stage, the quantitative data, in which patients' perceptions of control and self efficacy were represented as individual scores, were transformed into qualitative data by assigning categories of high, medium and low, to a range of scores. These

categories were created based on the possible range of scores on each subscale, and determined whether patients were considered to have high, medium or low perceptions at the beginning and end of their treatment. For example, the possible range of scores on the personal control subscale ranged from 6-30, with low perceptions of control being categorised as scores between 6 and 13, medium perceptions of control as being scores between 14 and 20 and high perceptions of control being categorised as scores between 21 and 30. These categories are shown in Table 11.1 in Chapter 11.

6.11.4 Stage 3: Data Integration

In the final stage, the qualitative and qualitised data (from the quantitative findings) were combined to explore the data for themes that were shared across each data set and for connections between the data sets. For example, the researcher explored the data sets to determine whether patients who reported higher perceptions of control in the quantitative data also reported higher perceptions of control within the qualitative data and whether there were connections between those patients reporting higher perceptions of control and the degree of self care that they carried out. Foster (1997) recommends presenting these findings in tabular form since this is useful to the reader for determining whether the patterns in the quantitative data are reflected in or supported by the qualitative data (Wendler, 2001) (see Appendix 10 for an example). These findings are presented in Chapter 11.

6.12 Summary

This chapter has detailed the methods chosen in the current study, including a discussion on the aims of the study, the study sample, and the design, methods and analysis strategies utilised to ensure the aims were met. The study followed a longitudinal, mixed method, patient focussed approach in exploring the perceptions and experiences of their involvement in self care, and their perceptions of control and self efficacy, in patients receiving chemotherapy in colorectal cancer. This approach emphasised the importance of the

individual patient in understanding their involvement in self care during treatment for cancer. This chapter highlighted that the design and methods chosen in the current study were important for providing insights into, and quantifiable data on, how patients' perceptions and experiences of being involved in self care, and perceptions of control and self efficacy change over the course of their chemotherapy treatment, and the ways in which these perceptions are associated with the degree of their involvement in self care. The following chapter discusses the conduct and findings from the pilot study, and the subsequent modifications made in preparation for the main study.

Chapter 7 Pilot Study

7.1 Introduction

Piloting is an essential stage in any research study as it can help to identify concerns, which need to be resolved or refined in preparation for the main study (Robson, 2002). This can include, issues relating to the study design, the research questions and data collection methods, sampling and recruitment strategies, and issues related to the practicalities of the daily management of the study during its conduct (Robson, 2002). The pilot phase in the current study specifically aimed to identify any issues related to the process of recruitment, estimate the intended recruitment target rates for the main study, and to test the feasibility, and patients' perceptions of the relevance and acceptability of the data collection tools and methods. The following chapter discusses the conduct of the pilot phase and the issues that were raised in relation to its aims.

7.2 Conduct of the Pilot Study

The pilot phase was conducted in the Beatson Oncology Centre, from October 2004 until February 2005, during one cycle (duration of one month) of the patient's chemotherapy treatment (first cycle of treatment). During this cycle, each patient (n=6) was asked to complete a questionnaire booklet and a self-care diary. This allowed enough time for patients to complete one set of data collection tools, as would be required in the main study, so as to determine the feasibility and acceptability of the questionnaire booklet and self care diary. Three patients were also asked to participate in one semi-structured interview to determine the relevance and acceptability of the content of the interview guide, and any issues that arose in relation to the conduct of the interviews. Eligible patients were identified (based on the criteria discussed in Chapter 6) from a review of the clinic lists generated by the clinical site and following discussions with clinical staff involved in the care of the patient. The researcher was introduced to patients and the purpose of the study and the pilot phase was explained to them.

The following sections describe the demographic characteristics of the patient sample that participated in the pilot phase before leading onto the findings from the pilot phase.

7.3 Population

A total of nine eligible patients were identified during the pilot phase. However, two patients did not attend the clinic on several occasions at their designated appointment times, therefore, seven patients were approached to consider participating in the pilot phase of the study. All seven patients consented to participate at this time, but one patient later failed to return to the clinic owing to a deterioration in their condition. Therefore, data for the pilot phase were returned from six patients. Table 7.1 highlights the demographic characteristics of the six patients who participated in the pilot phase.

| Patients in sample (n=6) | Frequency | Percentage |
|--|------------------|-------------------|
| Age | 56 yrs | - |
| Mean | 1 | 17% |
| 30-39yrs | 1 | 17% |
| 40-49yrs | - | - |
| 50-59yrs | 2 | 33% |
| 60-69yrs | 2 | 33% |
| 70-79yrs | | |
| Gender | | |
| Male | 6 | 100% |
| Female | - | - |
| Stage of Disease | | |
| Dukes' A | - | - |
| Dukes' B | 1 | 17% |
| Dukes' C | 4 | 66% |
| Dukes' D | 1 | 17% |
| Performance Status | | |
| 0 | 6 | 100% |
| 1 | - | - |
| 2 | - | - |
| Route of Administration of Chemotherapy | | |
| Intravenous Line (IV Line) | 6 | 100% |
| Hickman Line | 0 | - |
| Comorbidity | | |
| No pre-existing conditions | 2 | 33% |
| 1-2 pre-existing conditions | 3 | 50% |
| 3+ pre-existing conditions | 1 | 17% |
| Carstairs Deprivation Category | | |
| 1 | - | - |
| 2 | 3 | 50% |
| 3 | - | - |
| 4 | - | - |
| 5 | 1 | 17% |
| 6 | 2 | 33% |
| 7 | - | - |
| Social Circumstances | | |
| Lives alone | - | - |
| Lives with spouse/partner/family | 6 | 100% |

Table 7.1: Demographic characteristics of the pilot phase sample

The characteristics of the patients in the pilot phase were perhaps atypical to the expected characteristics commonly seen in this patient group. Patients who participated in the pilot phase were all male and ranged in age from 32-74 years. The absence of females who were eligible to be recruited during the time of the pilot phase is particularly notable. Rates on the incidence of colorectal cancer amongst men and women in Scotland appear to suggest that colorectal cancer affects equal proportions of men and women (in Scotland, colorectal cancer accounts for 14.7% and 11.3% of all cancers in men and women respectively (Information and Statistics Division (ISD), 2006). Therefore, the absence of females within the sample was unusual and precluded the identification of perceptions of both men and

women on the feasibility, relevance and acceptability of the data collection tools and methods.

It is also interesting to note the wide age range of the sample, particularly at the younger end of the spectrum. Colorectal cancer is typically associated with increasing age and is less common amongst younger people (NICE, 2004). In younger people, a diagnosis of colorectal cancer is typically associated with an underlying hereditary condition, such as, Familial Adenomatous Polyposis (FAP), which commonly develops into colorectal cancer in individuals between the ages of 40-50 years (Lynch and de la Chapelle, 2003), or Hereditary Non-Polyposis Colorectal Cancer (HNPCC), commonly developing into colorectal cancer in individuals by the time they are 45 years of age (Lynch and de la Chapelle, 2003). Indeed, one patient in the pilot phase sample, aged 32 years, had been diagnosed with FAP-colorectal cancer.

In total, one patient (17%) had been diagnosed with Dukes' Stage B colorectal cancer, four patients (66%) with Dukes' Stage C colorectal cancer, and one patient (17%) with Dukes' Stage D colorectal cancer. One patient had previously received chemotherapy treatment. All patients were classed as having a performance status of zero, meaning that they were fully active and able to carry on pre-disease performance without restriction (Oken et al, 1982) (the Eastern Cooperative Oncology Group (ECOG) performance scale on which this score is based is shown in Appendix 11), although most patients had experienced a minor level of co-morbidity (1-2 pre-existing conditions, with hypertension being the most common (n=3, 50%). In relation to social circumstances, all patients lived with their partner, spouse or family.

The Beatson Oncology Centre, being the largest specialist cancer centre in the West of Scotland, offers both local and regional oncology services to individuals from a broad range of geographical locations and socio-demographic backgrounds. Therefore, the range of

social class categories to which patients in the sample belonged to was not unexpected. Patients' social status was determined using the Carstairs Deprivation Categories (McLoone, 2004). Carstairs Deprivation Categories (which range from 1 to 7) are determined by postcodes and allow quantification of the extent of relative deprivation within a particular area. The use of this index is fairly standard for describing the socio-economic backgrounds of Scottish populations. The majority of patients in the pilot study sample belonged to deprivation category 2 which denotes a reasonably affluent area characterised by higher social classes, higher levels of car ownership and lower levels of unemployment (McLoone, 2004).

In the following sections, the findings from the pilot phase, in relation to the recruitment process, recruitment rates for the main study, and the feasibility, relevance and acceptability of the data collection tools and methods, are discussed.

7.4 Results

7.4.1 Recruitment Process

Aitken et al (2003) noted the importance of pilot testing the intended approaches to recruitment in order to streamline these processes in preparation for the main study. During the pilot study, the researcher elected to be present at the colorectal cancer clinic each week to ensure the appropriate identification of eligible patients and so that she could be introduced by clinical staff to patients in person in order to explain the purpose of the study and pilot phase. Permission to approach patients in the Outpatient Department of the hospital was sought from medical and nursing staff as discussed in Chapter 6. Several strategies for identifying and approaching patients were evaluated during the pilot phase, to determine the optimal approach that the researcher was to adopt during recruitment in the main study. Initially, the researcher sat in on the consultation between the medical staff and the patient (with the patient's permission). This allowed for easy identification of those patients who were eligible for the pilot phase, however, it quickly became apparent that

since there were several other consultations between patients and medical staff, occurring simultaneously, other patients could potentially be missed whilst the researcher was sitting in on a different consultation. It was, therefore, decided that clinic lists would be reviewed prior to the clinic and eligible patients identified to medical staff. The researcher then waited outside the consultation rooms, and was introduced to the patient once they had finished their consultation with the medical staff. This strategy ensured that both the researcher and medical staff knew of eligible patients that were attending the clinic that particular day, and that as few patients as possible were missed by the researcher.

7.4.2 Recruitment Rates

As one of the aims of the pilot phase, the researcher set out to establish the numbers of new patients attending the colorectal cancer clinic on a weekly basis, and from this, confirm the number of patients who were likely to be eligible for the main study and whether the intended recruitment targets ($n=35$) were reasonable. The researcher was advised by medical staff that on average there were 2-3 new patients each week, who would most likely be offered the Mayo chemotherapy regimen and thus, were likely to be eligible for the study. During the first two months of the pilot phase (November and December 2004), however, clinic attendance was significantly lower than expected and a total of only three patients were identified and recruited to the pilot phase. This may have reflected the timing of the beginning of the pilot phase, coinciding with clinic attendance being slightly lower towards the end of the year. A further four patients were identified and recruited in the third month of the pilot phase (January 2005), demonstrating a rise in clinic attendance at this time. Clinic attendance continued to rise after this time (3-5 new patients per week), therefore, it was deemed reasonable to assume that 5 patients per month, and hence, the intended sample size ($n=35$) would be an achievable target within the main study. It was decided that recruitment rates would be monitored during the main study on a three monthly basis, to determine whether these rates continued to be a reasonable target, and, in noting

the absence of females within the pilot phase sample, to ensure that the final study sample incorporated reasonable numbers of both men and women.

All data collection tools and methods as well as the patient information sheet were tested during the pilot phase for their feasibility, relevance to the patient population and patient acceptability. The following section discusses these findings, with particular reference to the ease of understanding and relevance of the patient information sheet, and data collection tools and the instructions for their completion, the acceptability of the layout and content of the questionnaire booklet and self care diary, and the content of the interview guide and the role of the researcher in the interview process.

7.4.3 Data Collection Tools and Methods

7.4.3.1 Patient Information Sheet

The patient information sheet was well received by all patients and they perceived it to have provided them with information relevant to the nature of the study and the requirements of patients' participation in the main study. One patient commented, however, that the nature of self care needed to be made simpler as he hadn't been sure whether the term referred directly to controlling and managing his side effects, or his usual participation in daily activities, such as, washing and dressing. Self-care was, therefore, defined for the purpose of this study, as being *'the activities that you carry out to prevent, control or relieve any side effects that you may experience during your treatment'*. This definition was discussed with the patient and perceived by them to clearly indicate the nature of self-care in the main study. This definition was, subsequently, used in the patient information sheet and printed on the front of the self-care diary, and when initially discussing the nature of the study with eligible patients. The researcher was aware, however, that this may have introduced a degree of bias since as a result of this, patients' responses may have been primarily concerned with managing the physical impact of their treatment, rather than the wider

aspects of their self care. This was discussed in Chapter 6 and is noted as a potential limitation of the study in Chapter 12.

Other instructions in the patient information sheet were well understood by patients. Minor changes included, highlighting key instructions in bold text to draw particular attention to them and clarification that patients would be asked to complete a new questionnaire booklet and self care diary on three separate occasions (one patient thought that the self care diary issued to them was designed to be completed over 3 cycles, rather than just one cycle, and subsequently completed the diary for a week, rather than a full month) (shown in Appendix 1).

7.4.3.2 Semi-Structured Interviews

7.4.3.2.1 Content of the Interview Guide

During the pilot phase, semi-structured interviews were conducted with three patients at the colorectal cancer clinic, to determine the relevance of the content of the interview guide. The findings from the interview guide identified that the questions within the interview were relevant and valuable in exploring patients' perceptions and experiences of control, self-efficacy and their involvement in self-care. In particular, patients' responses to the open questions, at the beginning of the interview, about how they had been coping in the preceding months since learning of their diagnosis, revealed key themes central to the study around peoples' coping styles, their attitudes towards their diagnosis and beginning treatment, and the impact that it had had on their lives and their families. These findings reinforced the importance of exploring these perceptions in the interviews and were consistent with the theoretical underpinning of the study (Leventhal's Self Regulation Model). The researcher acknowledged, however, that the findings revealed very little about patients' perceptions on the meaning of their self care and, therefore, the wording and emphasis on these questions within the interview guide were changed to encourage a

greater focus on this within the interview. The interview guides are shown in Appendices 6 and 7.

7.4.3.2 Reflexive Account

By reading the interview transcripts together with her research supervisor, the researcher acknowledged where she had missed patients' cues and where she could have encouraged further discussion on a particular issue. This highlighted the importance to the researcher of the need to critically review and learn from each interview transcript in the main study, paying close attention to where strategies could be used in future interviews, for stimulating further discussion and obtaining meaningful information on patients' perceptions and experiences. The researcher also acknowledged that strategies such as, note taking and using these to recap on the discussions with patients, were also useful strategies to use during interviews. Furthermore, in accordance with those strategies employed to enhance the quality and credibility of the qualitative data, the researcher became more aware of the importance of keeping accurate and detailed field notes during the interview process, for providing situational and emotional context to the interviews, and for providing a full and accurate account of patients' perceptions and experiences of their involvement in self care.

7.4.3.3 Questionnaire Booklet

The questionnaire booklet was generally well completed by all patients. All patients perceived the two questionnaires in the booklet to be relevant and easy to complete, taking them five to eight minutes, on average. The first questionnaire in the booklet, the Strategies Used by People to Promote Health (SUPPH), proved very straightforward, with all questions being completed by all patients. The second questionnaire, the Illness Perception Questionnaire (revised) (IPQ-R), however, contained a greater level of missing data. The first section of this questionnaire contains a list of side effects, to which patients are asked to tick yes or no, to indicate whether they have experienced the side effect or not. Although all patients answered well with regards to ticking the yes box if they had experienced the

side effect, the no boxes were left blank by two patients. It could have been assumed that because these boxes were blank, patients had indeed not experienced these side effects, however, this may have been misleading to assume that this was the case for both patients. Subsequently, to reduce the potential for missing data in the main study, the importance of answering all questions in the questionnaire were highlighted in bold in the completion instructions, and were emphasised in the accompanying verbal explanation of the study and how to complete the questionnaires.

All of the patients in the pilot phase perceived the layout of the questionnaires to be easy to follow. In accordance with the preferences of three patients, the questionnaire booklet was changed from an A4 to an A5 booklet for the main study. In this format, the questionnaire booklet looked easy to complete and was easy for them to carry it around with them (shown in Appendix 3).

7.4.3.4 Self Care Diary

Five patients perceived that the diary was relevant to them and easy to complete, taking them three to five minutes, on average, to complete each day. One patient, however, perceived that the diary looked *'too much to fill in'*, although when he was asked to explain this further, he was unsure as to the particular part of the diary that had made him think this. Nonetheless, despite his concerns, he managed to complete the diary for the given timescale reasonably well. Other patients commented, however, that the diary was useful in helping them to keep a record of how they had been feeling during their first cycle of treatment and the ways in which they had coped with this. They reported that completing the diary three times during their treatment would not have been a burden for them.

The content and the layout of the self-care diary were perceived by patients to be relevant and easy to follow. The diary had been developed in accordance with the findings from previous research, which revealed that a structured diary, containing a checklist of side

effects and self care actions, rather than relying on patients' free report, was more likely to enhance the accuracy and completeness of the self care information provided by patients (Nail et al, 1991; Foltz et al, 1996; Richardson and Ream, 1997 and Ream, 2002). Indeed, this was reflected by the fact that the diary was well completed by all patients.

The list of side effects and self-care activities, which was developed following a review of the literature and following validation by clinical staff at the clinical site where the research was being conducted, were reported as being appropriate and relevant to all patients. One further self care activity was added to the list ('*use throat sprays or lozenges*') in response to one patient's comment about the usefulness of this particular activity during his first cycle of treatment. A further question, which was identified from the pilot interviews, was also added to the diary. During the interviews, one patient stated that he was unlikely to carry out self-care until a side effect had occurred, meaning that he would take little preventative self-care action. This, therefore, prompted the inclusion of a question relating to the patients' preferences on the use of self-care to *prevent* a side effect from occurring, or to manage the side effect *once* it had occurred. It was intended that this information would be useful for providing an insight into patients' perceptions of when they deemed self care to be important during the main study. Each page of the diary was labelled to correspond with the day of the patient's cycle (for example, Day 1, Day 2, Day 3), however, one patient commented that it would have been easier to name the particular day at the top of each page, for example, Monday, Tuesday, Wednesday and, therefore, this was changed in the diary to reflect this comment.

As with the patient information sheet and questionnaire booklet, important instructions for completing the self-care diary were highlighted in bold to ensure accurate completion by patients, and a definition of self-care was printed on the front of the diary to remind patients what this meant. Like the questionnaire booklet, the diary was also changed from an A4 to

an A5 booklet for the main study, based on patients' preferences for this (an example of a page from the diary is shown in Appendix 4).

7.5 Summary of Pilot Results

The pilot phase of the study was particularly useful for identifying issues relevant to the recruitment process and intended recruitment rates for the main study, as well as for testing the feasibility, relevance and acceptability of the data collection instruments and methods. The pilot phase identified the importance of having a structured recruitment process in place and reinforced the value of the researcher attending the clinic each week to be introduced to patients and personally offer information to patients and discuss the study with them. It was also useful in confirming whether the intended monthly recruitment rates, and the intended sample size, for the main study was feasible. In particular, the pilot study helped to confirm that an expected sample size of 28 patients (based on the power calculation illustrated in chapter 6) (the researcher aimed to recruit 35 patients, however, to allow for attrition) was achievable. Furthermore, the pilot study highlighted the importance of monitoring recruitment rates on a regular basis within the main study to ensure that there was fair male and female representation.

All instruments and methods proved to be feasible and relevant to this particular patient group and, although generally perceived by patients to be acceptable, minor modifications were made to the questionnaire booklet and self care diary in accordance with patients' preferences. The conduct of the interviews raised some important issues for the researcher. In particular, they highlighted the importance of maintaining a close and reflexive consideration of her role in the interview process and the use of key strategies, such as, critically reviewing each transcript and note taking during the interviews, in enhancing the quality of the interview findings. The relevance and value of the content of the interview guide was reinforced by patients' responses and the themes that developed from these interviews, and emphasised the need to further explore areas such as patients' perceptions

on the importance of self care. The interview guide for the final interview in the main study, was, however, not piloted with patients at this stage, since the content of the second interview guide relied, in part, upon patients' responses in their questionnaire booklets and diaries throughout the duration of their full chemotherapy treatment.

It is also important to acknowledge that although the pilot phase findings were strengthened in one respect by the wide age range and social background of the sample, allowing a range of perceptions to be obtained in relation to these characteristics, they were limited in view of the fact that the sample comprised only men. Hence, the perceptions of women may have been quite different. The reason for the absence of females within the pilot phase sample is unknown and is surprising since attendance at the colorectal cancer clinic has continued to be spread consistently between males and females. It did, however, indicate the importance of regularly monitoring the characteristics of the sample within the main study, to ensure a diverse range of patients were recruited and thus, an accurate account of patients' perceptions and experiences of control, self efficacy, and involvement in self care was provided.

Chapter 8 Results

8.1 Introduction

The aim of the current study was to explore perceptions and experiences of patients' involvement in self care, and perceptions of control and self efficacy amongst patients receiving a six month course of chemotherapy treatment for colorectal cancer. The study was guided by the following research questions and hypotheses:

1. How do patients describe the meaning of self care and their involvement in self care and what are their perceptions of control and self-efficacy between the beginning and end of their course of chemotherapy treatment for cancer?
2. Does patients' degree of involvement in self care, and perceptions of control and self-efficacy change between the beginning, middle and end of their course of chemotherapy treatment?
3. Is patients' degree of involvement in self care associated with their perceptions of control and self efficacy at the beginning, middle and end of their course of chemotherapy treatment?

In relation to these research questions, it was hypothesised that:

1. The degree of self care carried out by patients and their perceptions of control and self efficacy will increase from the beginning to end of their chemotherapy treatment, and;
2. Patients who report a high level of control and self efficacy will carry out a greater degree of self care

The findings from the analysis are presented in the following four chapters. Chapter 8 considers the sample who were recruited to the study, in particular, the sample size, the sample demography, sample accrual, and the challenges encountered by the researcher in recruiting the sample. The management and quality of the data are also considered in

Chapter 8, along with a discussion of the psychometric properties of the quantitative data collection tools. Chapter 9 focuses on the findings from the analysis of the qualitative semi-structured interviews and the recurring themes which originated from these in relation to patients' perceptions and experiences of their involvement in self care. Chapter 10 focuses on the analysis of the quantitative data from the questionnaires and self care diaries and describes changes in, and associations between, patients' perceptions of their degree of involvement in self care, and their perceptions of control and self efficacy over their six month course of chemotherapy treatment. In these chapters, both the qualitative and quantitative data have been analysed separately as previously suggested (Tashakkori and Teddlie, 1998; Onwuegbuzie and Teddlie, 2003). Since the aim of the study design, however, is to interpret how both these types of findings contribute towards enhancing an understanding of patients' perceptions of control and self efficacy, and involvement in self care, Chapter 11 considers the triangulation of both the qualitative and quantitative data.

The following sections of this chapter consider the sample who were recruited to the study and their demography, how the study was affected by sample attrition, and the challenges that were encountered in recruiting the sample.

8.2 Sample Accrual

The recruitment phase in the study lasted 15 months and was conducted from March 2005 until June 2006. During this time, 46 patients were identified as being eligible to participate in the study. However, 13 of these patients were not approached to consider participating in the study. The reasons for this are summarised in table 8.1.

| Reason | Frequency |
|--|-----------|
| Researcher on annual leave | n=4 |
| Patient recruited to another research study | n=1 |
| Patient initially commenced treatment as part of a clinical trial | n=2 |
| Advised by clinical staff that patient was too anxious to be approached | n=1 |
| Patient admitted to the ward to commence treatment rather than being seen as an outpatient | n=1 |
| Unknown | n=4 |

Table 8.1: Reasons for eligible patients not being approached by the researcher

Two patients who were approached to consider participating in the study, declined to participate because they felt that they had too much going on at that particular time (n=1) or did not wish to discuss their thoughts and feelings about their diagnosis (n=1). Hence, in total 33 patients were approached, of which 31 consented to participate in the study (67% of those patients initially identified as being eligible to participate). The demography of the sample who consented to participate in the study is presented in the following section.

8.3 Demography of the Sample

Table 8.2 demonstrates the demographic characteristics of the sample who consented to participate in the study.

| Patients in sample (n=31) | Frequency | Percentage |
|--|------------------|-------------------|
| Age | | |
| Mean | 60yrs | - |
| 40-49yrs | 2 | 6% |
| 50-59yrs | 8 | 26% |
| 60-69yrs | 12 | 39% |
| 70-79yrs | 8 | 26% |
| > 80yrs | 1 | 3% |
| Gender | | |
| Male | 18 | 58% |
| Female | 13 | 41% |
| Stage of Disease | | |
| Dukes' A | 0 | - |
| Dukes' B | 6 | 19% |
| Dukes' C | 25 | 81% |
| Dukes' D | 0 | - |
| Performance Status | | |
| 0 | 29 | 93% |
| 1 | 2 | 7% |
| 2 | - | - |
| 3 | - | - |
| 4 | - | - |
| Route of Administration of Chemotherapy | | |
| Intravenous Line (IV Line) | 31 | 100% |
| Hickman Line | - | - |
| Comorbidity | | |
| No pre-existing conditions | 17 | 55% |
| 1-2 pre-existing conditions | 13 | 42% |
| 3+ pre-existing conditions | 1 | 3% |
| Carstairs Deprivation Category | | |
| 1 | - | - |
| 2 | 5 | 16% |
| 3 | 6 | 19% |
| 4 | 5 | 16% |
| 5 | 5 | 16% |
| 6 | 7 | 23% |
| 7 | 3 | 10% |
| Social Circumstances | | |
| Lives alone | 8 | 26% |
| Lives with spouse/partner/family | 23 | 74% |

Table 8.2: Demographic characteristics of the sample

All patients who consented to participate in the study were Caucasian, newly diagnosed and had undergone surgery within the previous 10 weeks of commencing the study. All patients were beginning the Mayo chemotherapy treatment regimen and receiving this via an intravenous line (IV line) rather than a Hickman Line. This was important to identify since Hickman Lines hold greater risks in terms of complications and infection, than an intravenous line and, therefore, may require a greater level of patients' self care.

Patients ranged in age from 40 to 81 years, with the mean age being 60 years. More males (58%) than females (41%) participated in the study, however, the proportion of females

who participated in the study was encouraging in light of the absence of females in the pilot study sample. All patients who consented to participate in the study had been diagnosed with either Dukes' B or Dukes' C stage colorectal cancer, with the sample comprising more patients with Dukes' C stage than Dukes' B stage. This is perhaps unsurprising since patients with Dukes' C colorectal cancer routinely commence chemotherapy following surgery (Maguire, 2002). During the study period, the decision to routinely offer chemotherapy treatment to patients with Dukes' B colorectal cancer remained a contentious issue (see Chapter 2), and it has only recently been accepted within medical circles that high risk patients with Dukes' B colorectal cancer should be considered for treatment with adjuvant chemotherapy (Professor Cassidy, personal communication, January 2007).

The majority of patients were classed as having a performance status of zero, meaning that they were fully active and maintained pre-disease performance without restriction (Oken et al, 1982) (the Eastern Cooperative Oncology Group (ECOG) performance scale on which this score is based is shown in Appendix 11). In terms of the level of existing comorbidity within the sample, the majority of patients did not have any pre-existing conditions. Those who did, however, suffered from a range of conditions including, Crohns Disease, cardiac conditions (hypertension, angina, atrial fibrillation, ischemic heart disease), and rheumatoid arthritis.

Patients demonstrated a reasonable spread of socio-economic backgrounds, as determined using the Carstairs Deprivation Categories (McLoone, 2004). As noted in Chapter 7, Carstairs Deprivation Categories (which range from 1 to 7) are determined by postcodes and allow quantification of the extent of relative deprivation within a particular area. The use of this index is fairly standard for describing the socio-economic backgrounds of Scottish populations. The slight majority of patients in this sample (n=7; 23%) belonged to deprivation category 6, which denotes a deprived area, characterised by lower social classes, lower levels of car ownership, and greater levels of unemployment and

overcrowding (McLoone, 2004). This is in contrast to the findings of the pilot study where the majority of patients belonged to deprivation category 2, characterised by higher social classes, higher levels of car ownership and lower levels of unemployment (McLoone, 2004). The range of socio-economic backgrounds to which patients belonged, however, is not surprising given that the Beatson Oncology Centre offers both local and regional oncology services to individuals from a broad range of geographical locations and socio-demographic backgrounds from across the West of Scotland. In terms of patients' social circumstances, the majority of patients in the study lived with a spouse or partner.

8.4 Sample Attrition

Although the researcher attempted to minimise sample attrition by ensuring that the instruments to be completed by patients were kept simple, and the lag time between data collection time points were fairly short, as noted in the literature (Singer and Willet, 1996; Ruspini, 2000), the longitudinal nature of this study, requiring patients' participation from the beginning to end of their treatment period, meant that some attrition was inevitable. In total, seven patients withdrew or were excluded from the study. The reasons for why patients do not participate in a study are important to consider since these can facilitate a better understanding of the recruitment challenges faced by the researcher during a study and can assist in determining the representativeness of the study sample. Two patients withdrew from the study because they perceived that the study required them to focus too much on their diagnosis and ensuing treatment, and that this was unhelpful for them in terms of adjusting to their diagnosis. Two patients consented to participate but did not return any quantitative data for the first cycle and, therefore, had to be excluded from the quantitative analysis. A further three patients discontinued their Mayo chemotherapy treatment regimen, and hence, were subsequently excluded from the study. Table 8.3 summarises the reasons for patients' withdrawal and exclusion from the study.

| Reason | Frequency |
|---|-----------|
| Withdrawals: | |
| Study required too much focus on diagnosis and ensuing treatment | n=2 |
| Exclusions: | |
| Did not return any data | n=2 |
| Wished to discontinue all treatment | n=1 |
| Mayo chemotherapy regimen discontinued because of renal failure (caused by severe toxicity) | n=1 |
| Mayo chemotherapy regimen discontinued because of disease progression | n=1 |

Table 8.3: Reasons for why patients withdrew or were excluded from the study

8.5 Demography of Participants and Withdrawals

Demographic data on those patients who were eligible for the study but declined to participate (n=2) was not obtained since access to patients' medical notes was only possible once they had given written informed consent for this, as per ethical approval received. Demographic data for the patients who consented to participate but then later withdrew or were excluded (n=7) was, however, available for comparison with those patients who continued their participation through to the end of the study. This data was important in order to compare both groups to determine whether there were any significant differences between the groups which may have influenced the study findings. Statistical analysis was performed on the demographic data of both groups using Pearson's chi square test for categorical data (Brace et al, 2006), for example, gender, stage of disease, level of comorbidity, socioeconomic status and social circumstances and the independent t-test (two tailed) for interval data (Brace et al, 2006) namely, age. The data in Table 8.4 identifies that there were no significant differences found between the groups in terms of age, gender, stage of disease, performance status, level of comorbidity, socioeconomic status and social circumstances.

| Variable | Statistical Analysis |
|----------------------|--|
| Age | t=0.753, df=29, p=0.458 (two tailed) |
| Gender | X ² =1.951, df=1, p=0.176 (exact significance test) |
| Stage of Disease | X ² =0.002, df=1, p=1.000 (exact significance test) |
| Performance Status | X ² =0.513, df=1, p=1.000 (exact significance test) |
| Level of Comorbidity | X ² =0.797, df=2, p=0.723 (exact significance test) |
| Socioeconomic Status | X ² =4.428, df=5, p=0.550 (exact significance test) |
| Social Circumstances | X ² =0.220, df=1, p=1.000 (exact significance test) |

* significant at p<0.05

Table 8.4: Statistical analysis revealing no significant differences between those patients who participated in the study and those who withdrew or were excluded

8.6 Quality of the Data

8.6.1 Degree of Missing Data

On recruitment to the study, all patients were given instructions on how to complete the questionnaire booklets and diaries and were reminded of these at each new cycle of data collection. Generally, the questionnaires and diaries were completed with ease and returned to the researcher. There were, however, some missing data within both the questionnaires and diaries, where these were completed and returned to the researcher, but had some answers or sections omitted. Table 8.5 demonstrates the degree of missing data found within each data set at each time point.

| Data Set | Number of missing entries identified | | |
|---------------------|--------------------------------------|--------------|--------------|
| | Cycle 1 (T1) | Cycle 3 (T2) | Cycle 6 (T3) |
| SUPPH (n=2262) | n=7 | n=4 | n=0 |
| IPQ-R (n=1794) * | n=9 | n=1 | n=1 |
| Diary (n=46,368) ** | N=16 | N=12 | N=8 |

* subscales included: personal control, treatment control, consequences, emotional representations

** subscales included; incidence of side effects, degree of self care carried out, specific self care activities carried out

Table 8.5: Number of missing entries within each data set

There was no missing data in the demographic data set since this data was primarily available within patients' medical notes or by asking the patient hence, this has not been included in Table 8.5. The majority of missing data in the questionnaires (SUPPH and IPQ-R) was found to be at the first time point (cycle 1/month 1/T1), but was more complete at the second (cycle 3/month 3/T2) and third (cycle 6/month 6/T3) time points. The extent of missing data in the questionnaires, however, was minimal in comparison with the number

of possible entries within these data sets. The increased proportion of missing data at the first time point may have been because by the second (cycle 3/month 3) and third (cycle 6/month 6) time points, patients were conditioned to the pattern and types of questions in each questionnaire, or may have felt more adjusted to their diagnosis and treatment by the subsequent time points, in comparison to the first time point, at the start of patients' treatment and shortly after they had received their diagnosis.

In relation to the self care diary, patients answered the following subscales well at all three time points: incidence of side effects, degree of self care carried out, and the specific types of self care activities they carried out. Five subscales however, were not completed well and each contained more than 40% missing items. These included: the interference of side effects, confidence to perform self care, self care performed to prevent side effects or when side effects occurred, and the helpfulness of specific types of self care activities. These subscales were subsequently excluded from the analysis in accordance with the guidance provided by Loewenthal (2001) as described in section 8.6.2. In particular, patients may not have completed these sections because they had previously recorded in the diary that they had not experienced side effects on that particular day and, therefore, may have perceived the self care section of the diary to be irrelevant. Furthermore, as discussed in greater detail in Chapter 11, the qualitative data revealed that patients found it difficult to determine the helpfulness of their self care and hence, this may explain why this section was not completed well. This is noted as a limitation of the study in Chapter 12.

In relation to the qualitative data, a total of eleven patients completed both interviews at the beginning and end of their treatment. However, two patients who consented to both interviews only ended up participating in one interview, namely the final interview. The reasons for this and the findings from the qualitative interviews are described in Chapter 9. Therefore, the total number of patients completing both interviews was 9 patients. Furthermore, for the purposes of merging the qualitative and quantitative data, only those

individuals for whom complete qualitative and quantitative data sets were obtained (n=8) were included in the analysis presented in Chapter 11.

8.6.2 Management of Missing Data

The management of missing data was handled in this study in accordance with the guidance provided by Loewenthal (2001) who stated that in cases where there were few missing data, for example, less than 40% of missing items in a subscale, the item can be substituted with the mean value for that variable. Menard (2002) states that this is likely to be more appropriate than simply deleting the case with the missing data from the analysis (Menard, 2002). Subsequently, where the subscales of the IPQ-R and SUPPH were found to have less than 40% of missing items in a subscale, the items were substituted with the mean value for the subscale in which the item was related to.

Loewenthal (2001) also stated that where there is a great deal of missing data in a particular subscale, for example, where more than 40% of the items are missing, that subscale can be excluded from the analysis since there is something suspicious about a subscale which has a great deal of missing data. Subsequently, as noted in section 6.1, there were five subscales of the self care diary that were excluded from the analysis (interference of side effects, confidence to perform self care, self care performed to prevent side effects or when side effects occurred, and the helpfulness of specific types of self care activities) (potential number of entries n=10,080) since they had more than 40% of missing items and for which a mean value could not be substituted because of their dichotomous nature. This is noted as a limitation of the study in Chapter 12.

8.7 Checking the Data Set

Loewenthal (2001) describes checking the data set as a three-stage process involving; eyeballing the data, where the data are scanned for errors; conducting frequencies for each variable, to check of unusual entries, which may have not stood out visually in the first

stage; and finally, manually checking the entries in the data set with that from the original data collection instruments. All three stages were carried out in checking the data set for errors. In conducting the frequencies of the variables, there were several notable errors, however, these all related to cases in which the value for missing data had not been recognised by the computer and were subsequently dealt with as described in section 8.6.2.

In relation to the third stage of the process, where all entries are manually checked against the patients' responses in their original data collection instruments, the researcher double-checked all entries within the demographic data set (n=279) and all entries within the questionnaire data sets (n=2262 for SUPPH, and n=1794 for the selected subscales of the IPQ-R, based on responses from 28 patients at T1, and 24 patients at T2 and T3) at all three time points. In the self care diary, since five subscales had been excluded because of missing data, only three subscales were checked for errors. Table 8.6 demonstrates the number of entries within each data set and the number of errors that were found in each data set at each time point.

| Data Set | Number of errors identified | | |
|---------------------|-----------------------------|--------------|--------------|
| | Cycle 1 (T1) | Cycle 3 (T2) | Cycle 6 (T3) |
| SUPPH (n=2262) | n=34 | n=8 | n=2 |
| IPQ-R (n=1794) * | n=14 | n=0 | n=1 |
| Diary (n=46,368) ** | N=20 | N=14 | N=16 |

* subscales included: personal control, treatment control, consequences, emotional representations

** ** subscales included; incidence of side effects, degree of self care carried out, specific self care activities carried out

Table 8.6: Number of errors identified within each data set

8.8 Reliability of Quantitative Questionnaires

Following the exclusion of subscales of the IPQ-R which were considered to be less relevant to the current study (identify, timeline (acute/chronic), timeline (cyclical), illness coherence, and causes), exclusion of the subscales of the self care diary which were less relevant to the final analysis (incidence of side effects) and those which contained more than 40% missing items (interference of side effects, confidence to perform self care, self care performed to prevent side effects or when side effects occurred, and the helpfulness of

specific types of self care activities carried out), Table 8.7 lists the subscales of the data collection instruments that were tested for their reliability in the current study.

| Variable | Subscale |
|--------------|---------------------------|
| IPQ-R | Personal Control |
| | Treatment Control |
| | Consequences |
| | Emotional Representations |
| SUPPH | Positive Attitude |
| | Stress Reduction |
| | Making Decisions |

Table 8.7: List of subscales which were tested for reliability in the current study

In particular, these subscales were tested for internal consistency reliability, which reflects the extent to which each item is measuring the same variable (Kline, 2000). Higher internal consistency refers to the case in which each item on a subscale measures the same variable to a greater extent and thus, are expected to show good reliability coefficients (Kline, 2000). A standard measure of internal consistency is Cronbach's alpha coefficient of which a value of 0.70 is considered as the minimum acceptable criterion of instrument internal consistency (Kline, 2000).

8.8.1 Internal Reliability of the Questionnaires

Table 8.8 demonstrates the Cronbach's alpha coefficients of the subscales of the IPQ-R and SUPPH that were included in the analysis for all three time points.

| Variable | Subscale | Number of items | Cycle 1/T1 (n=28) | Cycle 3/T2 (n=24) | Cycle 6/T3 (n=24) |
|--------------|---------------------------|-----------------|-------------------|-------------------|-------------------|
| IPQ-R | Personal Control | 6 | 0.818 | 0.796 | 0.709 |
| | Treatment Control | 5 | 0.716 | 0.777 | 0.542* |
| | Consequences | 6 | 0.833 | 0.686* | 0.539* |
| | Emotional Representations | 6 | 0.793 | 0.856 | 0.764 |
| SUPPH | Positive Attitude | 14 | 0.929 | 0.921 | 0.918 |
| | Stress Reduction | 7 | 0.769 | 0.882 | 0.866 |
| | Making Decisions | 3 | 0.425* | 0.208* | 0.503* |

* denotes coefficient of less than 0.70

Table 8.8: Cronbach's alpha coefficients of the subscales of the IPQ-R and SUPPH, included in the analysis at all three time points

Subscales which were demonstrated to have good internal consistency (>0.70) on at least two of the three data collection time points (personal control, treatment control, emotional representations, positive attitude, and stress reduction), were considered to show satisfactory internal consistency, and were comparable to previous testing of the subscales of the IPQ-R (Moss Morris et al, 2002) and the SUPPH (Lev and Owen, 1996; Eller et al, 2006). Subscales were excluded from the final analysis where they were found to have poor internal consistency (<0.70) on at least two of the three data collection time points. In the reliability analysis, Table 8.8 demonstrates that the 'consequences' subscale of the IPQ-R and the 'making decisions' subscale of the SUPPH showed poor internal consistency on two or more of the data collection time points during the study and hence, their reliability was questionable, prompting their exclusion from the final analysis.

The Cronbach's alpha coefficients reported in Table 8.8 for these subscales may reflect the fact that these scales contained comparatively few items, since a greater number of items are known to increase internal reliability (Kline, 2000; Loewenthal, 2001). The remaining subscales of the IPQ-R, which contained a similar number of items to the 'consequences' subscale, may also have suffered this problem to a certain extent since they show satisfactory but not particularly high Cronbach's alpha coefficients. As a point in case, in contrast, the 'positive attitudes' subscale of the SUPPH which contains 14 items demonstrated particularly good internal reliability at all time points throughout the study.

8.9 Recruitment Challenges

A homogenous sample of patients who had been newly diagnosed with colorectal cancer and were beginning the Mayo chemotherapy regimen (Poon et al, 1989) was recruited during this study. The recruitment of a homogenous sample ensured as far as possible that all patients were consistent in terms of the likely duration of their treatment (6 cycles over a 6 month period) and the likely pattern of side effects that they may experience during this period. This helped to ensure that patients' perceptions and experiences of control, self

efficacy and involvement in self care were drawn from a similar frame of reference and were not influenced by a combination of clinical factors (such as different types of tumour or stages of disease) since these may have created different self care needs and implications for self care. However, recruiting a homogeneous sample also led to limitations in the study which are also noted in Chapter 12. In particular, recruitment of this specific group proved challenging owing to the unanticipated number of clinical trials that began during the time of the study and which subsequently left fewer patients who were offered the Mayo chemotherapy regimen, and as a result were eligible to participate in the study.

In searching the literature for guidance on improving recruitment rates, Collins et al (1984) identified several strategies, two of which were considered as being feasible to implement in the current study. These included; (i) increasing the length of the recruitment period and, (ii) increasing the number of clinical sites. In light of these suggestions, the data collection period was extended by six months which proved relatively successful in increasing the patient numbers since one clinical trial was temporarily closed during this time.

The researcher chose to approach two further consultants at the Beatson Oncology Centre who regularly saw patients with colorectal cancer in their caseloads, to consider whether they would agree to patients being approached for the study. Both consultants agreed to this, however, owing to the vast range of treatment options offered to patients with colorectal cancer, only two further patients were identified from this approach, who were offered the Mayo regimen, and hence were eligible for the study. One consultant also ran a colorectal cancer clinic at another hospital (Crosshouse Hospital, Kilmarnock) was approached by the researcher and agreed to let the researcher identify and recruit any eligible patients who were under his care at this additional site. However, inclusion of an additional clinical site involved gaining further ethical and management approval, which took four months (end of December 05-end of April 06). Unfortunately, the approval was received too close to the researchers' recruitment deadline (June 06), which could not

feasibly be extended a second time and which left little extra time to recruit eligible patients. Furthermore, by the time the researcher had received appropriate permission to access these patients, there were newer treatment options being offered to patients and subsequently no patients were identified who were scheduled to begin the Mayo treatment regimen. Hence, no further eligible patients were identified within the remaining timeframe for the study by adding a second clinical site to the study.

Finally, Collins et al (1984) also noted that relaxing the inclusion criteria for a study was another potential strategy for improving recruitment. The researcher considered however, that this was not feasible for the current study and would introduce a degree of heterogeneity within the sample that the researcher had purposively intended to avoid. The reasons for this were noted at the beginning of this section and the importance of this is further considered in Chapters 6 and 12.

8.10 Summary

This chapter, the first of the results chapters, has discussed the sample of patients who were recruited to the study and their demography and how the study was affected by sample attrition. The processes involved in managing the data that was obtained and its quality, and the psychometric properties of the quantitative data collection tools have also been considered in this chapter. Finally, the challenges encountered by the researcher in recruiting the patient group during the study, and the approaches taken to counteract these challenges were discussed. The following chapter focuses on the findings from the qualitative semi-structured interviews. In particular, it details the sample of patients who participated in the interviews and their demography, and the recurring themes which originated from the analysis of the interviews in relation to patients' perceptions and experiences of their involvement in self care.

Chapter 9 Qualitative Analysis

9.1 Introduction

The following chapter describes the findings from the analysis of the semi-structured interviews, which were conducted at the beginning and end of patients' chemotherapy treatment. The chapter begins by presenting the demography of the patients who participated in the interviews and then focuses on the recurring themes and sub themes which originated in relation to the meanings that patients in the study attached to self care and how they became involved in their self care. The recurring themes and sub themes which originated in relation to patients' perceptions of control during their treatment are also presented. Further analysis and interpretation of these themes and how they relate to the findings from the quantitative data set is considered in Chapter 11 in which the findings from the qualitative and quantitative data sets are merged.

9.2 Demography of the Sample

The recruitment of the sub sample of patients who participated in the semi-structured interviews was described in Chapter 6. The demography of the sub sample of patients who participated in the semi-structured interviews is shown in Table 9.1.

| Case | Age (yrs) | Gender | Social Class | Stage of Disease (Dukes') | Performance Status | Level of co-morbidity | Social Circumstances |
|------|-----------|--------|--------------|---------------------------|--------------------|-----------------------|---------------------------|
| 1 | 59 | Male | 4 | C | 1 | 1-2 | Lives with spouse/partner |
| 2 | 69 | Female | 6 | C | 0 | 1-2 | Lives with spouse/partner |
| 8 * | 68 | Male | 6 | C | 0 | 3+ | Lives with spouse/partner |
| 10 * | 74 | Male | 4 | C | 0 | 1-2 | Lives alone |
| 11 | 59 | Male | 7 | C | 0 | 0 | Lives with spouse/partner |
| 12 | 69 | Male | 7 | C | 0 | 1-2 | Lives with spouse/partner |
| 17 | 69 | Male | 5 | C | 0 | 0 | Lives with spouse/partner |
| 19 | 74 | Male | 2 | C | 0 | 1-2 | Lives with spouse/partner |
| 22 | 55 | Female | 3 | C | 0 | 1-2 | Lives alone |
| 24 | 49 | Female | 5 | B | 0 | 0 | Lives with spouse/partner |
| 31 | 76 | Male | 6 | C | 0 | 1-2 | Lives alone |

* participated in final interview only

Table 9.1: Demographic characteristics of patients who participated in the semi-structured interviews

The sub sample of patients who participated in the qualitative semi structured interviews comprised both men and women, ranging in age from 49-76 years, and included patients living in a range of social classes from 2-7, as determined using the Carstairs Deprivation Categories (McLoone, 2004). Only one patient was diagnosed with Dukes' B stage colorectal cancer and one had a performance status of 'one', whilst the remainder had been diagnosed with Dukes' C and had a performance status of zero, as determined by the Eastern Cooperative Oncology Group (ECOG) performance scale (Oken et al, 1982). This reflects the predominance of patients with Dukes' C staged colorectal cancer and a high performance status amongst patients in the full sample. In relation to patients' social circumstances, the majority of patients in the sub sample lived with their spouse and family.

A total of nine patients completed interviews at both the beginning and end of treatment. Two further patients completed the final interviews at the end of treatment only, despite consenting to both interviews at the start of the study. This was because in one case, the patients' appointment was repeatedly missed and the researcher considered that it would be

inappropriate to interview the patient one month beyond the first cycle of treatment. In the other case, the patient stated that he did not have anything to say at the first interview but would still be keen to participate in the final interview at the end of treatment. The findings from the interviews conducted with these two patients have been included in the discussion in this chapter but have not been included in Chapter 11 where the findings from the qualitative and quantitative data have been merged.

9.3 Analysis of the Interviews

9.3.1 Developing the Thematic Structure

Semi-structured interviews, using the interview guides shown in Appendices 6 and 7, were conducted with the sub sample of patients (n=9) at the beginning (within 4 weeks of them beginning their first cycle of treatment) and at the end (within 4 weeks of them finishing their last cycle of chemotherapy) of their chemotherapy treatment. These were used to explore the meanings that patients ascribed to their self care, and the ways in which patients were involved in their self care and whether these changed during the course of their treatment (over a 6 month period), and their perceptions of control and how these changed during the course of their treatment (over a 6 month period). The semi-structured interviews were analysed at both time points using framework analysis (as described in Chapter 6). Concrete descriptions of experiences of self care and perceptions of control were made for each patient to facilitate an overall understanding and allow the researcher to become completely familiar with the data (Pope et al, 2000; Green and Thorogood, 2004). This prompted a process of open coding which allowed ideas to emerge which were then grouped into key themes and sub themes (Pope et al, 2000; Green and Thorogood, 2004). Finally, the data was constructed thematically to identify the content of each theme and sub theme (an example of which is shown in Appendix 8) and was then organised into summaries and tables highlighting the key themes that were identified for each patient (known in framework analysis as ‘charting’ and ‘mapping’, an example of which is shown in Appendix 9) (Pope et al, 2000; Green and Thorogood, 2004). This allowed themes and

sub themes to be identified within and between interviews and was important for mapping the importance of each of the themes and sub themes and for identifying possible connections between these themes (Pope et al, 2000; Green and Thorogood, 2004).

9.3.2 Thematic Content

There were three key themes in relation to patients' perceptions and experiences of self care which emerged from both the first and second interviews. These included, the meaning of self care to patients, and physical self care strategies and emotional self care strategies that they carried out during their treatment. Each theme consisted of several sub themes (shown in Tables 9.2-9.8). These themes and sub themes arose from the questions "what does self care mean to you" "can you tell me how you are coping/have coped during your treatment", "what are you doing/did you do to manage the effects of your treatment", and "what is self care to you", and from patients' accounts of the way that their treatment had impacted upon them. In their responses to these questions, patients revealed what self care meant to them and distinguished between the different kinds of impact that they were experiencing; physical and emotional.

Patients' descriptions of how they were coping with their treatment suggested that they perceived there to be a distinction between their physical and emotional self care needs, and hence, different strategies were employed to meet these needs. Patients were quite clear that their physical strategies were employed to help them cope with and manage the side effects caused by their chemotherapy treatment itself. On the other hand, patients' emotional self care strategies were employed in an effort to manage the emotional disruption, anxiety and stress provoked by their diagnosis of cancer, as well as the effects of their chemotherapy treatment. Patients' descriptions highlighted that whilst they regarded their physical self care at this time as being quite specific, emotional self care was viewed as something wider than this and was often related to how they would manage themselves in their normal social lives.

It was evident in all of the transcripts that some patients perceived themselves to have a high degree of control over their self care whereas others perceived themselves to have little control. The qualitative analysis was also extremely useful for exploring some of the factors that contributed towards perceptions of high control and those that contributed towards perceptions of a low degree of control. Hence, there were two key themes in relation to patients' perceptions of control. These included, the degree of control patients perceived themselves to have and the factors influencing their perceived degree of control. Each theme consisted of several sub themes (Tables 9.7 and 9.8). These themes and sub themes arose from the questions "how much control do you feel you have at the moment", "how much control do you feel you have over managing the impact of your treatment" and "how important is it that you have a degree of control over the impact of your treatment". Exploratory questions were used to follow up patient's responses to these, for example, if patients responded to say that they perceived that they had a great deal of control, they were asked to consider why that was. From responses to these questions, it was possible to determine the degree of control patients perceived themselves to have and suggest some of the factors contributing towards their perceptions.

Two issues in relation to the thematic content of the interviews, however, are important to note. Firstly, it was noted in Chapter 6, that the definition of self care used to frame the study was initially conceptualised as the management of the physical effects of undergoing treatment, largely owing to the current literature and Musci and Dodd's (1990) definition of self care (as discussed in Chapter 3), and may have been a source of bias within the study. This definition was presented to patients when the study was initially discussed with them and was used to structure the self care diary. As a result, this may have led patients to view their self care in physical terms. Secondly, the researcher acknowledges that little information emerged from the interviews on patients' perceptions of self efficacy. There are two possible reasons for this. In particular, patients may not have been able to distinguish the differences between their perceptions of control and perceptions of self

efficacy, and as such, this may have required the researcher to explore this in further depth with patients. This is further discussed and acknowledged as a limitation of the study in Chapter 12.

9.4 Presentation of the Thematic Analysis

The thematic content of the qualitative semi-structured interviews is presented in this chapter as follows:

- Meanings of self care
- Experiences of self care – beginning of treatment
- Experiences of self care – end of treatment
- Degree of control
- Factors influencing perceptions of control

Section 9.5 presents the findings in relation to the meanings that patients in the study ascribed to their self care. This section considers the meanings that emerged from both the first and second sets of interviews conducted at the beginning and end of patients' treatment. In sections 9.6 and 9.7, the findings from the first and second sets of interviews in relation to patients' experiences of their involvement in self care, and the nature of the strategies that they carried out, have been discussed separately. This is for ease of reading and to allow the reader to observe the comparison between patients' involvement in self care at the beginning and at the end of their treatment.

Section 9.8 presents the findings in relation to the degree of control that patients perceived themselves to have during their treatment and presents some examples of these perceptions. Section 9.9 presents the findings in relation to the factors which influenced patients' perceptions of control. In these sections, the findings from the first and second sets of interviews have been discussed together since there appeared to be little change (within the

qualitative data) in the degree of control that patients perceived themselves to have between the beginning and end of their treatment.

The thematic content presented in each of the sections is structured based on the frequency with which each patient reported a particular theme or sub theme. Counting themes within a data set is one approach that the researcher can use in order to easily identify the themes and sub themes which repeatedly emerge from the data (Polit and Hungler, 1998; Barbour, 1999; Burns and Grove, 2003) and hence, determine those themes and sub themes which are considered to be more important or significant to the participants (Burns and Grove, 2003). Furthermore, counting the frequency of themes within a data set is a good method of verification of the findings (Miles and Huberman, 1994). Therefore, the researcher considered that using frequency counts to present the qualitative findings in a chronological order, although not compulsory in a qualitative research study, was a valuable way of highlighting the centrality of patients' meanings of self care and the types of self care activities they carried out during their treatment, to provide a detailed understanding of patients' involvement in self care.

The themes and sub themes in Tables 9.2-9.7 are listed in chronological order based on the frequency with which they occurred within the data sets and are discussed in chronological order in the following sections. The numbers following each of the themes and sub themes in the tables refer to the sections of the following chapter in which their content is described.

9.5 Meaning of Self Care

The meanings that patients in the study ascribed to their self care emerged, in both the first and second sets of interviews, from questions such as, "what does self care mean to you" or "why do/did you carry out self care", and "is/was self care important to you". Several sub

themes relating to the individual meanings that patients spoke of were identified within this theme. These sub themes are shown in Table 9.2.

| Key themes | Sub themes | No of patients who identified sub theme |
|----------------------|--|---|
| Meaning of Self Care | Limiting the impact of treatment (9.5.1) | n=9 |
| | Being normal (9.5.2) | n=7 |
| | Keeping fit and healthy (9.5.3) | n=5 |
| | Using own judgement (9.5.4) | n=4 |
| | Being positive (9.5.5) | n=3 |
| | Problem solving approach (9.5.6) | n=2 |

Table 9.2: Themes and sub themes relating to the ‘meaning of self care’

9.5.1 Limiting the Impact of Treatment

This sub theme was formed in response to patients’ comments about the meaning of self care being directed at limiting the physical and emotional impact of their chemotherapy treatment and the perceived importance of their self care. This sub theme was identified by nine patients. When asked what self care meant, these patients immediately related self care to managing physical side effects and finding ways of alleviating the emotional impact of their treatment. In particular, several patients spoke of the meaning of self care as being able to limit the impact of physical side effects, principally, through using medication and following health professionals’ advice, but also being able to find ways of adapting to side effects and alleviating the emotional impact by finding ways to reduce anxiety and stress. These perceptions are demonstrated in the following examples from the analysed data.

“I had control over the mouth because I had the hydrocortisone so I knew as long as I took that I was in control of the situation. You felt as if, no I don’t need to panic, if it gets sore through the night, I can take a tablet.” Patient 10

“What I’ve been doing is a wee bit of deep breathing...it did relax me, deep breathing does relax you.” Patient 10

“I take what’s prescribed to me and I follow their [health professionals] guidelines.” Patient 12

“I just don’t eat, I take fluids, lots of different kinds of fluids...I’ve tried to get into the habit of the second week, I just don’t eat.” Patient 12

9.5.2 Being Normal

The sub theme of being normal arose from the accounts of patients who made reference to the notion of being normal or maintaining normality when asked what self care meant to them. This sub theme was identified by seven patients. Several of these patients commented that they did not intend on changing their lifestyle whilst undergoing treatment, and hence, to them, self care meant being able to continue their participation in normal activities and routines. Self care was also seen as simply getting on with life and maintaining one’s independence wherever possible. These perceptions are highlighted in the following examples.

“Self care is only doing what you’ve got to do to get on with your life at that stage and as much as you can do at that stage.” Patient 1

“It’s never really impaired any of my activities...I still take the dogs out for a walk and things like that...I’ve been to two or three dances in the past six months but it’s not in any way hindered my social life. You’ve just got to get on with life.” Patient 8

“It [self care] is about your mental state as well and trying to be as normal as possible and trying to just be you and do everything...keep the family going and do everything you used to do before. I just want to be the Mum I always was and the Wife I was.” Patient 24

9.5.3 Keeping Fit and Healthy

This sub theme arose from the direct quotes from one patient and was reflected in other patients' accounts. In total, five patients referred to this theme when considering what self care meant to them. In particular, patients suggested that self care was about being fit, which was important in helping them to cope with the impact of treatment, and stated that gentle exercise was important for improving strength, which was seen to contribute to their meaning of self care. The following quotes are examples from the analysed data of these perceptions.

“The fitter you can keep yourself, the better that helps you cope with illness. Because the fitter you are, the more active you are and the better you become.” Patient 1

“I do quite a bit of walking, I think walking's quite good for you...I know exercises that builds your strength up.” Patient 19

“I think it [self care] is just doing the things that keep you fit and healthy you know eating and drinking healthily and that was part of being tuned into my body and listening to my body.” Patient 22

9.5.4 Using Own Judgement

The majority of patients in the sample revealed that they carried out a great deal of self care during their treatment, however, few patients actually spoke of taking charge of their own self care, preferring to rely solely on the use of medications or the advice given to them by health professionals, in an unquestioning manner. Five patients, however, referred to the meaning of self care as a process of using their own judgement, which formed the title of this sub theme. The following quotes from the analysed data demonstrate how several patients used their own judgement in taking control over their own self care needs.

“You’ve got to judge it, if I felt I’d to stop taking the medicine...I would try that and see how successful it was. That’s me taking the decision...the doctors say take five times a day...now I only take it when I need it...when I think it’s going to benefit me. That’s how I went through it, just making a judgement myself.” Patient 12

“I’m not a great one for taking things if I don’t think they’re needed. I only took them [tablets] when I felt I needed to take them and I just judged that myself.” Patient 19

“I’ve taken anti-diarrhoea tablets once where I had a few days that were bad but mostly I prefer not to take those cos I’m still coming to terms with the stoma and what it’s doing.” Patient 22

One patient, also suggested that part of self care was knowing what you could do yourself but also knowing at what point to seek advice from a health professional and why this was considered to be a last resort for this patient.

“I think the thing about self care is that you’re not out on your own. If there was a problem I know the people I’d phone for help you know. Self care’s fine as long as you know what you’re doing and you’re confident with it but there’s always going to be something that’ll crop up and [you need] to know when to go and ask about it.” Patient 24

“I’m quite a strong person anyway and I’m quite sensible I know about decision making and things like that. If I’d have constantly had to ask advice about things...it’d have made me feel that someone else was running my life. I know my body, I know my limitations and the decisions I can make.” Patient 24

9.5.5 Being Positive

This sub theme arose from patients' accounts of what self care meant to them. Three patients identified this sub theme. In particular, patients' commented that trying to stay positive throughout their treatment was one of their main goals and that they were determined to not let the effects of the cancer and treatments diminish their attitude, as shown in the following examples.

“When you're home you know that you can say well I can do this, I can do that...anything you're doing fills up the day...so what I was trying to do was look forward to something. On a Monday, I'd go down and have couple of drinks and I'd look forward to that cos it's something to do, seeing my mates, talk about the football...just being positive.” Patient 10

“I've never let anything beat me and so I don't intend to let this beat me.” Patient 12

“I'm a really positive person...I just thought I'll just throw everything at this right at the start and then I can get on with my life rather than not taking the treatment and waking up every day and worrying you know...I've got more positive days than I have negative days” Patient 24

9.5.6 Problem Solving Approach

The final sub theme relates to the nature or process of self care, rather than its meaning specifically, although it was formed from patients' accounts of the meaning of self care like the other sub themes and, therefore, has been reported here. Two patients identified this theme and highlighted that they perceived their self care to be a process of problem solving and experimentation, and one which is learned over time. The following examples from the analysed data highlight this.

“You go on your experience and you take it from there and you try the things that you know work and when they stop working, you start going along a different route and work through it.” Patient 1

“There’s always something...always a way of doing what you want or achieving what you want.” Patient 1

“I like to try and get some fresh fruit and vegetables...that’s difficult cos I’m still experimenting with those so healthy eating’s something I’m working on just now.” Patient 22

“The first month you don’t really know what to expect and you wonder whether it will be exactly the same the second month. It’s not exactly the same the second month but then maybe the third month is the same as the first but you do know when it’s going to happen and you do have similar types of symptoms and things so I think there’s a pattern you come to expect.” Patient 22

The following sections consider patients’ descriptions of their experiences of being involved in treatment at the beginning and end of their treatment. Section 6 firstly deals with the themes that emerged from the first set of interviews, conducted with patients at the beginning of treatment. Section 7 then goes on to explore the themes that emerged from the second set of interviews, conducted with patients at the end of their six month course of treatment.

9.6 Experiences of Self Care – Beginning of Treatment

9.6.1 Physical Self Care Strategies

The theme of ‘physical self care strategies’ was formed from the range of strategies that patients carried out to manage and adjust to the physical impact of their treatment (see Table 9.3). These strategies included, finding ways to treat and adapt to the side effects of

treatment, relying on the expertise and knowledge of health professionals, and physically preparing oneself for undergoing chemotherapy treatment.

| Key themes | Sub themes | No of patients who identified sub theme |
|-------------------------------|---|---|
| Physical Self Care Strategies | Treating side effects (9.6.1.1) | n=9 |
| | Relying on health professionals (9.6.1.2) | n=9 |
| | Adapting to side effects (9.6.1.3) | n=6 |
| | Giving yourself the best chance (9.6.1.4) | n=3 |

Table 9.3: Themes and sub themes originating from the first set of interviews (n=9) relating to physical self care strategies

The use of the term ‘physical self care strategies’ to encompass these strategies was also derived from previous research which has distinguished between the use of self care strategies to manage the physical aspects of illness, for example, cancer-treatment related side effects (Dodd, 1988; Nail et al, 1991; Foltz et al, 1996; Richardson and Ream, 1997; Borthwick et al, 2003; Wong et al, 2006) from other aspects such as mental and emotional adjustment. This distinction seemed to be reflected in the majority of the patients’ accounts of the difference between their physical and emotional self care needs however, as noted in section 9.3.2, the theme of physical self care strategies may have emerged as a result of the conceptualisation of self care used to frame the study (see Chapter 12 for further discussion of this).

The following section considers the sub themes which fell within the key theme of physical self care strategies, how they were formed and examples provided to illustrate the centrality of these sub themes in patients’ management of the physical impact of their chemotherapy treatment.

9.6.1.1 Treating Side Effects

This sub theme arose from patients’ accounts of what they did to help manage the physical side effects of chemotherapy treatment. When asked about how they were coping with their treatment, all patients referred without hesitation to the ways in which the side effects of

their treatment had begun to, or might affect them over the course of their treatment, and how they intended to treat these. Therefore, this sub theme became known as ‘treating side effects.’ ‘Treating side effects’, was described by all nine patients. This reflects the predominance of the meaning of self care amongst patients being aimed towards limiting the impact of treatment. The majority of patients spoke of their intention to treat the most common side effects that they had been told about, including nausea and vomiting, diarrhoea, and mucositis.

A range of treatment strategies were reported by several patients, including, drinking plenty fluids, taking greater care with oral hygiene and using regular mouthwashes and carrying out wound care. The predominant measure used to treat side effects, however, appeared to be the use of medications. This was often the first measure used by patients to manage the physical side effects of treatment, as typified in the following examples.

“I suppose if I do feel sick, I’m just hoping that the anti-sickness tablets they’ve given me is going to work and if not, apparently I’ve got to go to the doctor...perhaps he’ll prescribe something else.” Patient 2

“I think you’ve only got two options...medication, and if that doesn’t work then seek advice” Patient 11

“I’ve got treatment there if I’ve got any diarrhoea or anything...I can get remedies for anything that happens to me” Patient 17

“Once I noticed it was too liquidy [the stoma output] so I took the loperamide and magic...the next lot was back to normal so I felt very confident in that loperamide...all I have to do is take that. As I say, I’ve got the loperamide for the diarrhoea, the domperidone for the anti-sickness...so I feel these are the tools I’ve got to combat the side effects.” Patient 31

9.6.1.2 Relying on Health Professionals

This sub theme was evident in all nine patients' accounts of how they managed the physical impact of chemotherapy treatment. Like the reliance on medication for treating physical side effects, the role of health professionals was often one of the first things patients mentioned when asked about the management of the physical impact of their treatment, reflecting their meaning of self care as being focussed on managing the impact of treatment. Some patients perceived that they only had two options for self care, namely, reliance on medication and reliance on health professionals.

Although the extent to which relying on health professionals featured as a key strategy in each patients' physical management differed (for example, some patients relied on health professionals as an immediate measure whilst others chose to seek health professionals' advice as a latter resort or only when their own self care stopped working), their accounts suggested that it was a strategy which helped them to not only treat their side effects but also gave patients a sense of reassurance that they were not being left on their own. Relying on health professionals was also seen to be important in enhancing their perceptions of control, since several patients perceived themselves to be in a situation in which they had little control. The following examples from the analysed data highlight the use of this self care strategy.

“There may be things that you should be doing or medication you should be taking beforehand, if that's the case, I expect the professionals to tell me that I'm doing the right thing as it's happening. If it's something they cannae predict, then I'm wasting my time trying to second guess it, I'll nae bother.” Patient 1

“Everybody's got their own way of adjusting I suppose...I would just speak to that girl [the nurse] up at [the hospital]...she's the one that's

been through it before with different other people and I suppose her experience, a wee bit of it might pass on to me.” Patient 11

“I believe I’m in the hands of the specialists and whatever the specialist thinks they’ll do, is the answer, there’s no way I’m going to argue against what the specialists decide. I follow their guidelines you know”

Patient 12

As noted earlier, the extent to which patients relied on health professionals at the beginning of their treatment often differed. In particular, the above quotes suggest that for several patients, contact with health professionals was considered a first option in their management of the physical impact of their treatment. On the other hand, there were others who saw depending upon health professionals as a last resort, only to be considered when one had exhausted their own potential for self care, when their side effects worsened, or when they believed it really was necessary.

“I’m happy to go away with the tablets and just manage myself...I’m managing my wound now myself you know. The district nurses are just coming once a week to check that everything’s okay but I’m cleaning it right, I’m packing it right, everything’s fine. I’d rather do it myself at half 8 in the morning and then get up and get out for the day instead of sitting waiting for someone to come in.” Patient 24

“Taking care of myself...no I’m happy...I am in control of that and happy about it. Who knows further down the line if my symptoms get worse, I might be happier to off load that to a professional...” Patient 24

“[If own self care didn’t work] I’d phone the ward and get a bit of advice, tell them what I’d been doing and anything else they could suggest for me...it’s good to know that that’s there if things did get a wee bit out of hand.” Patient 31

9.6.1.3 Adapting to Side Effects

This sub theme arose from patients' accounts of what they did to help manage the physical impact of chemotherapy treatment. These strategies, rather than focusing on treating specific side effects, focussed on the ways in which patients adapted to, or compensated for, the impact of these effects on their lives. This sub theme was, therefore, referred to as 'adapting to side effects' and was described by six patients in the sample. Like in the previous sub themes, this self care strategy reflected patients' meanings of self care being directed at limiting the impact of treatment.

Several examples of the ways in which patients adapted to, or compensated for, the impact of physical side effects on their lives were identified. For example, many patients chose to manage the impact of fatigue and reduced physical strength by carrying out more sedentary activities, resting, and carrying out less strenuous activities. The following examples from the analysed data typify these strategies.

"If it means sitting down for a couple of days and lying back then that's what you've got to do" Patient 1

"I'm tending to do more sedentary things at home...I work a lot on the computer and things like that, just do development work that means I can work with my head instead you know." Patient 22

"I had a couple of days feeling nauseous but I just stayed at home and just sort of chilled out and read a book...and just took it very easy."
Patient 31

Other strategies, such as doing some gentle exercise were also used to help lessen the impact of fatigue.

“The more active you are, the better you become.” Patient 1

“I think it’s just a natural disinclination when you’re tired really although I do try to have a little walk outside every day if I can.” Patient 22

“I was pretty much my own self...a wee bit weak and tired...sitting there I could drop off to sleep so I try to, each day, go for a wee walk and get some exercise and air about me and each day I got stronger.” Patient 31

Further strategies used by patients to adapt to, and compensate for, the impact of physical side effects on their lives focussed on reducing food intake, to avoid exacerbating feelings of nausea, or to increase intake of nutritional supplements such as, build-up drinks, when patients felt that they could not eat as well as they normally may do. The following examples from the analysed data highlight these strategies.

“My throat almost felt like it was closing up for about 5 days and I couldn’t eat properly for a few days and I was on the fortisips [nutritional drinks].” Patient 22

“I did reduce my food intake ...I didn’t want to overload the stomach or anything like that just in case it’d bring it up and I kept it very light indeed and that seemed to help.” Patient 31

The visible effects of having surgery and chemotherapy for cancer, for example, hair loss and the impact of this on daily life, were also commented on by several patients. Hence, they employed strategies for disguising hair loss as suggested in the following examples.

“I’ll just put a bunnet on, that’s my remedy...I’ll just stick my bunnet on and I’ll be alright” Patient 19

“I know I can get a wig if I lose my hair” Patient 24

9.6.1.4 Giving Yourself the Best Chance

This sub theme originated from the direct quotes from one patient when asked about how they were coping with their chemotherapy treatment, and was reinforced in the accounts provided by other patients. ‘Giving yourself the best chance’ referred to the ways in which patients’ prepared themselves physically for undergoing treatment and was identified by three patients. Several strategies were used by patients, including, eating well, resting, and keeping physically fit, and seemed to be related to the meaning of self care as being focussed on ‘keeping fit and healthy’.

“I’m already preparing for anything happening because I’ve always got a good appetite regardless, I still eat well, I’m trying to exercise, keep moving so that I’m giving myself the best chance I can have at the time.”

Patient 1

“I do tend to have a rest in the afternoon. I’m still eating very well so far...the first day I had the chemo I went home and said get the dinner on quick in case I’m not able for it.” Patient 2

“The immediate thing is taking care of my body and making sure that I do everything I possibly can with hygiene, diet, all these things to...to keep me as fit as possible...to cope with this chemo and beat this.”

Patient 24

9.6.2 Emotional Self Care Strategies

The theme of ‘emotional self care strategies’ was formed from the range of strategies that patients carried out to manage and adjust to the emotional impact of their treatment (see Table 9.4). An example from the analysed data demonstrates how this theme was distinguished from the physical self care strategies that patients employed in coping with the physical impact of their treatment, as discussed in the previous section.

“ [Self care is] the immediate things like taking care of my body and making sure that I do everything I possibly can with hygiene, diet, all these things to keep me as fit as possible...to cope with this chemo and to beat it...it’s [also] got a wider aspect, it’s about your mental state as well I think and trying to be as normal as possible and trying to just be you and do everything that you know...keep the family going and do everything you used to do before. It’s a whole big thing, it’s not just the physical...it’s the mental side of it as well and just trying to keep going and be the person I always was.” Patient 24

In addition to distinguishing the difference between physical and emotional self care strategies, this quote reveals one of the key strategies that patients used to manage the emotional impact: maintaining normality, which is discussed in the following section. Other examples of emotional self care strategies falling within this theme included, learning what to expect not dwelling on the effects of the cancer and its treatments, rationalising and comparing, and keeping a positive attitude (Table 9.4).

| Key themes | Sub themes | No of patients who identified sub theme |
|--------------------------------|---------------------------------------|---|
| Emotional Self Care Strategies | Learning what to expect (9.6.2.1) | n=8 |
| | Maintaining normality (9.6.2.2) | n=7 |
| | Rationalising and comparing (9.6.2.3) | n=6 |
| | Not dwelling (9.6.2.4) | n=6 |
| | Beating the cancer (9.6.2.5) | n=6 |
| | Avoiding the outside world (9.6.2.6) | n=2 |

Table 9.4: Themes and sub themes originating from the first set of interviews (n=9), relating to emotional self care strategies

The following discussion considers the sub themes which fall within the key theme of emotional self care strategies, how they were formed, and examples provided to illustrate the centrality of these sub themes in patients’ management of the emotional impact of being diagnosed with, and beginning treatment for, cancer.

9.6.2.1 Learning What to Expect

This sub theme arose from patients' accounts of the emotional impact of being diagnosed with, and beginning treatment for, cancer, and the strategies that had helped them to manage this impact. Patients reported that they wished to know what they might face during their treatment and that this knowledge was helpful in helping them to feel prepared for events, and hence, enhanced their perceptions of control. The sub theme of 'learning what to expect' was identified by eight patients.

The importance of learning what to expect during cancer treatment, so that one could appropriately prepare for and manage its effects, is highlighted in the following example.

"I came here and saw [the doctor] and he explained that some people have side effects and others don't...it's a hit or a miss at the start. So then I started the chemo and I was okay when I had the chemo but four days down the line, I started being sick and the vomiting just got worse and it just became horrendous....I went nearly a whole week where I was continually vomiting and it was a friend of mine, she's a retired nurse and she phoned on the Saturday and I said I can't speak, cos my tongue was cleaving to the roof of my mouth I had no saliva, and when she heard that she came down and said you're severely dehydrated she says I think we'd better get you into hospital so eventually I was taken into [the hospital]. It took them a fortnight to get me back on my feet, they were worried about my kidneys." Patient 31

He continues by alluding to the impact that this experience also had on his perception of control.

“I felt as though I was totally out of control with it...I couldn't control it...I thought that something needs to be done, I couldn't cope with this with every cycle of chemo if this was going to be the side effects.”

Patient 31

Several strategies were employed by patients in helping them to feel prepared for the physical and emotional impact of their treatment. These included, learning how one's body worked, meaning that patients could identify when something was wrong; seeking information; and sharing experiences with fellow patients. Some examples of patients' use of strategies such as, information seeking and sharing experiences are illustrated below.

“I've become very modern, I've got a top of the range computer system...so we're able to do things like that; go on and see anything about cancer...anything about the drug... so we did all that sort of thing. It is important you know that you know where you're going and what's happening.” Patient 12

“If you have a problem, whatever sort you're in, if you can talk to someone who's been there before or had that experience then I think it does help. If you've got a wee bit of preparation for it it helps, they might not have all the answers but it might give you an idea of which road you walk on.” Patient 1

“[A friend] she said something about the Maggie's Centre...apparently you can go in for a coffee, go in for a chat and meet other people who've got the same problem..” Patient 2

9.6.2.2 Maintaining Normality

This sub theme arose from patients' accounts of the emotional impact of being diagnosed with, and beginning treatment for, cancer, and the strategies that had helped them to manage this impact. The idea of normality seemed an important issue for patients, particularly given that many patients referred to the meaning of self care as 'being normal' and also given the range of strategies that patients employed in maintaining a sense of normality in their lives. Its' importance was reflected in the transcripts of seven patients and included strategies such as, continuing with normal routines, not giving up the things that they enjoyed doing, maintaining a sense of identity, continuing to protect and care for the family, and generally trying to prevent the effects of their cancer or treatment from impacting unfavourably upon their lifestyle. Examples from the analysed data below highlight patients' self care strategies in helping them maintain a sense of normality.

"I'm a single malt man, I love drinking a single malt, single malts all over the world and I'll never give it up and I smoke a pipe, I've smoked a pipe for 30 odd years and I don't intend on giving it up." Patient 12

"I can work my life around that you know [the treatment]. I still go up and down to the caravan and take the dog a walk...I walk four miles a day." Patient 17

"I just get out and nothing stops me, I'm always on the go, it's just the way I live my life. When my friends phone and say can I do your ironing, can I do this, I just say no just come round and chat cos it's being with people that matters more now than anything." Patient 24

Maintaining a sense of identity and maintaining one's position within the family, was also seen as an important way of maintaining normality as illustrated in the following example.

“[self care is] trying to be as normal as possible and trying to just be you and do everything...keep the family going and do everything you used to do before.” Patient 24

*“I just want to be the Mum I always was and the Wife I always was.”
Patient 24*

9.6.2.3 Rationalising and Comparing

This sub theme arose from patients’ reflection on their own experiences of being diagnosed with and beginning treatment for cancer. Many patients perceived that they were lucky that their cancer had been diagnosed early, had been surgically removed and was now being treated with chemotherapy and perceived themselves to be lucky in comparison to others around them who they viewed as being worse off than themselves. The analysis suggested that this strategy was relevant to the meaning of self care as ‘being positive.’ Hence, the sub theme of rationalising and comparing was formed being identified by six patients.

The process of undergoing chemotherapy treatment itself was rationalised through patients perceptions of the aim of the treatment, for example, it was seen as necessary or as a precautionary measure. Patients also rationalised by describing the treatment as being short term, believing in its efficacy and by focusing on the future once the treatment was over. Thus, they often perceived the physical and emotional impact of treatment that they may experience to be a small price to pay in turn for a greater chance of “cure” and often rationalised, or even made light of these, in their accounts of their experiences of side effects. In these reflections, side effects were believed to be temporary and something that was short lived, something that had to be endured or were simply seen as no more than an inconvenience.

“The treatment has got to be done and that’s it for me. I mean if you don’t take the treatment, then you’ve got serious consequences later on.

It's got to be done, if it wasn't it could be a bigger problem at a later date. I find I've just got to do it there's no other thing for it because it could make things even worse if I left it and then if something did happen, it'd take even more treatment to get it fixed so you hit the problem right away rather than leave it. I think it's a small price to pay [referring to the side effects].” Patient 11

“I have confidence in [the doctor] what he said is that he has got all the cancer and it has gone and I also accepted what [the doctor] said that this [the chemotherapy] is a precaution. I accept that this is short term...the side effects are something I've got to endure. Because it's short term and because an end's in sight that's okay, I can cope with that fine” Patient 22

“I know this isn't going to go on forever and I will get back to my own fitness I feel that I'm doing something and the treatment is going to work. It's a small price to pay [referring to hair loss] and I'll manage fine.” Patient 24

Many patients often found themselves comparing their situation to other patients who may have been younger than themselves, or were perhaps perceived as having more to live for, or comparing themselves to other patients who had experienced particularly severe side effects, had become quite debilitated, or for whom a chance of being “cured” was no longer possible. The following examples from the analysed data illustrate these perceptions.

“I just keep saying when I see all these people in trolleys and wheelchairs, I'm just saying thank god I'm not as far as them, whether I get as far as them in the future who knows but I just keep saying well if they can cope with it surely I can.” Patient 2

“There’s always somebody worse off...always somebody worse around the corner...I sit here and I’m 69 you know I’ve did well in life and you see wee weans coming in here and young folk and you think life’s been cruel to them. I mean I’ve seen life, I’ve wandered the world, taken the wife around the world and it’s when you seen these younger generation in here...wee weans... teenagers...life’s cruel to them cos they’re not experiencing life that’s what it is...you know I feel sorry for them.”

Patient 12

“When you get to my age you get a bit philosophical. If you’re going to die, you’re going to die. I’m nearly 75 so I’ve had good innings...but I’m hoping that I’ve got another 5 or 6 years.” Patient 19

One patient also rationalised her diagnosis of cancer as having a profound effect on her self perception and her relationship with her husband. Hence, she had rationalised the cancer as being associated with a degree of transformation, which brought about a positive change, as reflected in the following example.

“It’s been a really big wake up call, cos I was obsessed about lots of things before and maybe didn’t spend as much time with my husband as I did and should have done you know...cos I was working full time and I felt as if I had to prove something that I was “supermum” and you don’t realise sometimes that we are “supermum” no matter whether you live in a fantastic house you know so that’s really been a big wake up for me, I’m certainly not as bad as I used to be. I’m more into spending time with my friends...I mean I’ll walk out and leave the dishes now and if someone’s going to come and pick me up and take me out now I think that’s more important. It’s been good for the two of us [referring to her husband] because it’s changed the way we are with each other as well,

we've learned a lot more about each other that we just were too busy to pick up on before...it's definitely changed my outlook on life and what matters more now you know.” Patient 24

9.6.2.4 Not Dwelling

This sub theme arose from patients' accounts of the emotional impact of being diagnosed with, and beginning treatment for, cancer, and the strategies that had helped them to manage this impact. The title of the sub theme was taken from direct patients' quotes and was reinforced by the content of the accounts of other patients, and was identified as a key self care strategy by six patients. The idea of 'not dwelling' on the emotional impact of the cancer and the effects of its' treatments encapsulated a number of strategies such as, taking each day at a time, not worrying about things before they happen, not thinking too far ahead or dwelling on what the future may hold, not looking for information in addition to what had already been provided, and focusing on relaxation techniques and distraction to relieve anxiety and distress. This was important for staying positive and was also suggested as being associated with the meaning of self care as 'being positive'. The following examples from the analysed data highlight patients' use of this self care strategy.

“You always come up against situations you cannae do anything about or cannae do anything with...but worrying about it before hand never helps. I don't see the point in second guessing and I know as the treatment goes on seemingly the side effects can get worse...but until that happens, I'm not particularly going to worry about it.” Patient 1

“I just felt very tensed up and found myself pacing up and down the floor and doing deep breathing exercises. They probably did help. Watching television, programmes I would never watch but just something to keep my mind off it. Keeping myself busy...that's the way I tend to cope.” Patient 2

“I don’t seek information. I’d rather not look too far ahead...just take one step at a time.” Patient 11

9.6.2.5 Beating the Cancer

This sub theme arose from direct patient quotes and patients’ accounts of their experiences of managing the emotional impact of being diagnosed with, and beginning treatment for, cancer. Six patients suggested that this was an important self care strategy that they used at the beginning of their treatment. Several patients described their desire to adopt a fighting spirit and think positively about the future. Patients coped by facing the treatment head on, focusing on survival and achieving goals, in an attempt to “beat the cancer”. Such a strategy seemed to be important to patients for taking charge and maintaining a strong sense of control over the effects that the cancer and its treatment had on their bodies and their lives. This is exemplified in the following examples from the analysed data.

“You can sit and watch the world go by if you like. Again it’s not in my nature, it never has been, I mean you’ll never achieve anything and you’ve just got to do it as far as I’m concerned... there’s no other choice.” Patient 1

“I’ve got my mind set and the time March comes next year, and I finish treatment and that’ll be me and it’s nothing worth bothering about more than making sure you’re going to survive at the end of the day that’s how I look at it...nothing’s going to beat me...that’s how I’ve coped with everything through life, I’ve never let anything beat me and so I don’t intend to let this beat me.” Patient 12

“I’m a really positive person...I just thought I’ll just throw everything at this right at the start and then I can get on with my life rather than not taking the treatment and waking up every day and worrying you know...I’ve got more positive days than I have negative days” Patient 24

Others identified that they were able to maintain a positive attitude and a strong perception of control by believing in the efficacy of the medication they had been provided with to treat the physical side effects from their treatment.

“[the medication] help me cope because if they said right you’re going to be sick and we can’t give you anything for it, then that’d be more stressful.” Patient 2

“I felt very confident in that loperamide...all I have to do is take that. As I say, I’ve got the loperamide for the diarrhoea, the domperidone for the anti-sickness...so I feel these are the tools I’ve got to combat the side effects.” Patient 31

9.6.2.6 Avoiding the Outside World

This sub theme arose from patients’ accounts of the emotional impact of coping with the consequences of chemotherapy treatment. This theme was less strongly reflected in the data, being identified by two patients. In particular, patients suggested that they tended to manage feelings of anxiety or issues related to their body image, by avoiding contact with friends and family. They also avoided being out in public to protect themselves from being forced to disclose to the wider public that they were undergoing chemotherapy treatment, as exemplified in the following example.

“I think if that did happen [hair loss], I’d tend to sort of shy away and not go out very much” Patient 2

“Why is that?” Researcher

“I suppose you’re aware of people saying oh she’s had chemo., is that her own hair or what. I’d probably shy away from meeting people you know...I would feel very self conscious, there’s no doubt about it I’d feel

self conscious, because my hair's not very thick, it's fine and I would definitely feel self conscious.” Patient 2

The following examples from the analysed data highlight that ‘avoiding the outside world’ was employed by patients as a strategy when feelings of anxiety, depression or frustration made them feel that they were not up to socialising and spending time with friends and family.

“Under normal health if you were feeling a bit down, you'd just put your coat on and go out and visit someone but I feel I don't want to do that. I would like to but I just feel that I'm not at the stage where I want to go out...even yesterday I was supposed to meet my friends up the city but I didn't go cos I just feel I'm not ready for that yet. If I do go out it's jump in the car, up here, the church, that's as far as I've been.” Patient 2

“When I've got side effects I can be quite mumpy and miserable because it's a lot of low level things rather than a major pain or something that's making you terribly ill, and that for someone like me is more of a nuisance because I feel impatient with myself. I don't want to talk to people as much because my mood's a little lower than it was you know or if I've had mouth ulcers for a few days, I can't be bothered talking to people you know. I think people find it difficult because I am usually quite ebullient. I'd rather be myself when I talk to people so I maybe avoid answering the phone and things when I'm having a few days where I maybe want time to myself because of that you know...I do avoid too much contact when I'm not feeling great.” Patient 22

9.6.3 Summary

The findings from the first set of interviews suggested that patients carried out a range of self care strategies to manage the physical and emotional impact of being diagnosed with, and beginning treatment for, cancer. Patients carried out a number of self care strategies at the beginning of their treatment designed to manage the physical impact of their treatment. These included, treating side effects, such as, nausea and vomiting, diarrhoea and mucositis, principally through the use of medication; relying on the expertise and experience of health professionals, because of doubts about their personal abilities to become involved in self care; adapting to, and compensating for, the impact of treatment-related side effects; and giving yourself the best chance by physically preparing yourself for the physical impact of treatment. As noted in this chapter, these themes may have arisen as a result of the physical connotations of the conceptualisation of self care used to frame the study. This is further considered in Chapter 12.

The principal emotional self care strategies used by patients at the beginning of their treatment focussed on learning what to expect, by seeking additional information and sharing experiences with fellow patients; maintaining a sense of normality by continuing with one's normal activities and routines and maintaining a sense of identity and purpose; rationalising the impact of being diagnosed with and undergoing treatment for, cancer and comparing their situation to others around them; not dwelling on the effects of the cancer and treatment by avoiding focusing on the future and finding ways to relax and distract ones' self; adopting a fighting spirit in an effort to beat the cancer effects of treatment; and by avoiding contact with the outside world.

The following section considers the nature of the self care strategies that patients employed towards the end of their treatment, as identified in the second set of interviews that were conducted at the end of patients' treatment.

9.7 Experiences of Self Care – End of Treatment

9.7.1 Physical self care strategies

Similar to the first set of interviews, the theme of ‘physical self care strategies’ in the second set of interviews was formed from the range of strategies that patients carried out to manage and adjust to the physical impact of their treatment. These strategies were broadly similar to those highlighted in the first set of interviews, in particular, treating side effects and adapting to side effects, and also the degree of reliance by patients on health professionals that was demonstrated in patients’ accounts (Table 9.5).

| Key themes | Sub themes | No of patients who identified sub theme |
|-------------------------------|---|---|
| Physical Self Care Strategies | Treating side effects (9.7.1.1) | n=11 |
| | Adapting to side effects (9.7.1.2) | n=11 |
| | Relying on health professionals (9.7.1.3) | n=7 |

Table 9.5: Themes and sub themes originating from the second set of interviews (n=11), relating to physical self care strategies

The following discussion considers the sub themes which fall within the key theme of physical self care strategies in order of importance to the majority of patients, how they were formed and examples provided to illustrate the centrality of these sub themes in patients’ management of the physical impact of their chemotherapy treatment during the course of their treatment.

9.7.1.1 Treating Side Effects

This sub theme arose from patients’ accounts of what they did to help manage the physical side effects of chemotherapy treatment. This sub theme was identified by all 11 patients, and like in the first set of interviews, reflects the predominant meaning of self care which was to limit the impact of treatment. There was little variation identified in the use of strategies relevant to this theme between the first and second sets of interviews. Like in the first set of interviews, patients referred to treating symptoms of nausea and vomiting, diarrhoea and mucositis with similar strategies that they had used at the beginning of their treatment, indicating consistency in their use over the course of their treatment. In addition,

to these, two new strategies that they mentioned related to the use of eye drops and skin creams.

Patients' use of medication for treating physical symptoms was again highlighted as the most prominent strategy. As in the first set of interviews, the use of medication helped to enhance perceptions of control since they perceived that they were able to control treatment related side effects and prevent them from worsening and impacting negatively on their lives. Medication was also believed to offer reasonable and instant relief from side effects.

“I had control over the sore mouth because I knew I had the hydrocortisone...I was taking that four times a day so I knew as long as I took them I was in control of the situation. You felt as if no I don't need to panic, if it gets sore through the night, I can take a tablet...I knew that this was helping [the hydrocortisone].” Patient 10

“[I had]...sore mouth at times but I just got tablets...the hospital gave me tablets. I had senna for the constipation and loperamide and domperidone [for the sickness]. I didn't take anything to ward it off, I just waited til they came on and then took it and they more or less worked...everything they gave you worked.” Patient 19

“I didn't feel great but I felt I knew I could get the anti-sickness tablets, mouthwashes and things like that.” Patient 22

The accounts from one patient in particular consistently suggested reliance on using medications took predominance over alternative strategies, such as information seeking, and how confidence in the efficacy of the medication helped to give a sense of control over managing the physical impact of his treatment. The following examples from the analysed data illustrate this.

“When the sickness started again I thought oh here we go we’re on the merry-go-round again but I had the medication, the domperidone and the loperamide for the diarrhoea and I combated it with that. I had so much more confidence in the medication that when the vomiting started the second time I felt able to carry on with the medication.” Patient 31

“I didnae bother [to look for information on self care strategies]I just relied on the medication cos I had great confidence in that cos I knew that over the last five cycles, it kept me from vomiting and controlled the diarrhoea. I realised the medication could suppress the extent of it and it was working.” Patient 31

Despite patients’ reliance on medication to treat the physical impact of their treatment and beliefs in its’ efficacy, there were several patients who also expressed concerns or doubts about its’ use and efficacy, highlighting the tension between the necessity of the medication and their concerns over its use. These accounts highlighted that although medications were considered to be essential in helping patients to control the physical impact of their treatment, its use was viewed by some patients to be a last resort, only to be taken when side effects became severe enough to warrant its use. The following examples from the analysed data highlight patients’ concerns over the use of medications and their doubts about its efficacy in preventing and controlling treatment-related side effects.

“I don’t want anything to interfere [with the chemo]. I kind of wait until the last minute if I really do need it [a sleeping tablet] you know but I’m very cautious.” Patient 2

“I’m the kind of person that doesn’t like taking pills, I’d rather grin and bear it and if that doesn’t work or I feel it getting worse, then I will take it..” Patient 11

“Despite the fact I knew I could get these things [the medication] I knew I would have the symptoms anyway so I knew that they would alleviate it a little but they wouldn’t stop it...it was almost as if the symptoms were going to be inevitable.” Patient 22

9.7.1.2 Adapting to Side Effects

This sub theme arose from patients’ accounts of what they did to manage the physical impact of their treatment. Like in the first set of interviews, these strategies focussed on the ways in which patients adapted to, or compensated for, the impact of side effects on their lives. In terms of the content of this sub theme, it was identified that patients used a greater range of adaptive strategies in the second set of interviews. This sub theme was identified by all 11 patients in the second set of interviews, and reflected the meaning of self care as being intended to limit the impact of treatment.

There were several strategies used by patients, relevant to this sub theme, which remained unchanged from the first set of interviews, for example, disguising the visible effects of chemotherapy, such as, hair loss; reducing food intake or increasing intake of nutritional supplements; sleeping more and resting when necessary; and carrying on with some gentle exercise when possible to build up physical fitness and stamina and to help alleviate the cumulative impact of fatigue that many patients described.

“If I tire, I slow down or just stop and do something else. I find if I stop what I’m doing and do a different type of task then that seems to work for me. You’ve just got to work at it and get the levels [fitness levels] back up. If there’s something I cannae do, I just shelf it and I’ll do it when it comes up again and just get on with it. If I’m tired and I’m really feeling like that, I’ll go and have a lie down.” Patient 1

“What I did find during the tiredness if I did fight it, say it was a nice sunny, frosty day and my wife’d say fancy taking the dogs out, we’d maybe go over to the moor but as long as I was on the move I was alright, as long as I was out doing [something].” Patient 8

““Pulse five, week three was the worst I felt in as much as I felt there was some sort of leaden weight on my body. I was so fatigued, I couldn’t do particularly much but I just decided well I can’t do it and that’s it so I rested.” Patient 24

Additional strategies adopted by patients over the course of their treatment, which were not identified with such importance in the first set of interviews, focussed on a greater need to manage dietary needs and eating patterns. In particular, patients described the importance of monitoring their weight loss, learned what foods to avoid which might aggravate side effects, drinking using a straw, eating small regular meals and light foods, or taking a liquid diet when feeling nauseous or experiencing mucositis. The following examples from the analysed data highlight these strategies.

“I had the sore mouth, it wasn’t ulcers it was just you couldn’t take anything hot so I used to drink liquids through a straw.” Patient 2

“I just don’t eat, I take fluids, drink lots of different kinds of fluids...I’ve tried to get into the habit of the second week I don’t eat.” Patient 12

“I was taking soups to begin with and I really couldn’t tell you what they were but they went down I didn’t have to chew them and they weren’t in my mouth for that long.” Patient 19

9.7.1.3 Relying on Health Professionals

Like the findings from the first set of interviews, this sub theme emerged in the second set of interviews. It was suggested by six patients in their accounts of how they managed the physical impact of their chemotherapy treatment. Like in the first set of interviews the extent to which patients relied on health professionals varied based on their doubts about their self care knowledge and their own abilities to take charge of their self care.

“I think I’m a bit cautious with being on chemo. I’m aware that the chemo is a poison going through my system, and I don’t want anything to interfere with that...I prefer to ask rather than just go with what somebody else says you know. I was just quite happy to do what they[the health professionals] said because they know best.” Patient 2

“I just took these pills and if they weren’t working then I would phone the [nurse] who’s very good, she put me in the picture. I did have a sore head but I wasn’t sure whether I’d be able to take medication...aspirin or whatever.” Patient 11

Indeed, the language used by one patient in particular, revealed that he did not perceive himself to have a role in treating the physical effects caused by his treatment and hence, did not perceive himself as having control over this.

“I almost sailed through it you know I mean once they’d controlled the mucositis, I’d no problems what so ever. I didn’t think I could have got the full lot if my mouth was going to be sore all the time but once they’d controlled that I didn’t have much problems at all.” Patient 10

“If the staff or doctors suggested anything, I would take it. What I’ve tried to do is follow their advice because they know best.” Patient 10

This was also evident with others, as suggested in the following examples from the analysed data.

“I don’t have control over it...the nurses and the doctor were in charge of what was happening. The [doctor] reduced my dosage because I had diarrhoea that was quite severe at that time and that helped, but no I’ve not had a great deal of control.” Patient 17

“I did all the recommended things and it certainly helped to alleviate the symptoms but no it didn’t make me feel in control and no it didn’t make me feel I could prevent anything. I didn’t feel it was effective enough for me to think I’m in control of this. At no point did I feel in control of it...I knew I couldn’t stop the symptoms and prevent them and I felt really quite down and depressed about it.” Patient 22

The language used by patients was also important for revealing how patients learned to take control over their self care decision making. The following examples from the analysed data suggest that patients learned to judge the nature of side effects for themselves and based their use of self care, in this case taking medication, on these judgements.

“You’ve got to judge it...I mean you get a feeling of sickness but you’re not sick so I felt if I’d to stop taking the medication. I would try that and see how successful it was. That’s how I went through it, just making a judgement myself. I just decided to look at it each day and if I felt better I wouldn’t touch it [the tablets].” Patient 12

“I’m not a great one for taking things if I don’t think they’re needed. No, I didn’t take them [the tablets] constantly at all, I only took them when I felt I needed to take them and I just judged that for myself which was easy enough to judge.” Patient 19

9.7.2 Emotional Self Care Strategies

Like in the first set of interviews, the theme of ‘emotional self care strategies’ was formed from the range of strategies that patients carried out to manage and adjust to the emotional impact of living with cancer and undergoing treatment. The strategies falling within this category were similar to those in the first set of interviews and included, learning what to expect during treatment, rationalising and comparing and focusing on maintaining normality (Table 9.6). Some differences in the centrality of these themes and their content, however, were noted between the first and second sets of interviews as revealed in the following discussion. In particular, rationalising and comparing emerged as a more central theme in the second set of interviews than it had in the first set. Furthermore, focusing on the future was a new sub theme which emerged from the second set of interviews.

| Key themes | Sub themes | No of patients who identified sub theme |
|--------------------------------|---------------------------------------|---|
| Emotional Self Care Strategies | Rationalising and comparing (9.7.2.1) | n=9 |
| | Focusing on the future (9.7.2.2) | n=9 |
| | Learning what to expect (9.7.2.3) | n=8 |
| | Maintaining normality (9.7.3.4) | n=6 |
| | Not dwelling (9.7.2.5) | n=6 |

Table 9.6: Themes and sub themes originating from the second set of interviews (n=11), relating to emotional self care strategies

The following discussion considers the sub themes which fall within the key theme of emotional self care strategies, how they were formed, and examples provided to illustrate the centrality of these sub themes in patients’ management of the emotional impact of living with, and undergoing treatment for, cancer.

9.7.2.1 Rationalising and Comparing

This sub theme arose from patients’ reflections on their own experiences of living with, and undergoing treatment for, cancer and was identified as an important self care strategy by nine patients. Like in the first set of interviews, patients rationalised their own experiences of living with the impact of cancer and its treatment by comparing their experiences to those of other patients that they had encountered or to ‘horror stories’ that they had

previously heard about how cancer and the effects of treatment can manifest themselves. Again patients, perceived that the treatment had been necessary to achieve a greater chance of cure but that they viewed themselves as being lucky. This was based on their perception of their treatment, in which many reported that the treatment had been bearable and that they had experienced few or fairly minor physical side effects which had not been too troublesome for them. These strategies were important in helping patients to feel a sense of control over what was happening to them and were reflected in their meanings of self care as being directed at 'being positive'.

"The treatment's not been bad. I mean some of them [other patients] are sitting there for a couple of hours on a drip and that must be daunting you know. I've got to admit, although I've taken cancer, I feel I've been quite lucky I really do." Patient 2

"I would say that on the whole, the side effects over the last 6 months have been very mild. You know the horrendous things you hear about people talking about...going and having a shower and your hair falls out in clumps and you wake in the morning with all your hair out. I expected to be ill...to what extent I wasn't sure but I expected to be incapacitated to quite a large degree and I found that not to be the case." Patient 8

"I was expecting much worse just because some people suffer so terribly with the chemo and I think of that as well because it wasn't as bad as I thought it was going to be. I was able to cope with that, I just felt oh well if that's all I'm going to get, I'm getting away lightly." Patient 24

Others referred to the treatment being easy, short term and that the six month period during which they had received their treatment had passed quickly as demonstrated in the following examples from the analysed data.

“It’s strange...you start at month one and this is now month six and I don’t feel it’s been six months...it’s just flown through. I’ve got to admit, it hasn’t been too bad, looking back on it, it hasn’t been too bad.” Patient 2

“I didn’t think it was going to last forever, I knew I was going to be okay. You knew what was causing it [the side effects] and you knew it was going to go away...you were able to thole it when you knew it was going to go away.” Patient 19

“I was very structured so I think that’s what made it go quite quickly. The chemo itself was nothing like I expected...it was just so easy you know...I can’t honestly say I felt dreadful, it was very bearable.” Patient

24

9.7.2.2 Focusing on the Future

This sub theme arose from patients’ accounts of the emotional impact of living with, and undergoing treatment for, cancer and their strategies for managing this impact. ‘Focusing on the future’ was identified as a valuable self care strategy by nine patients in the second set of interviews but was not seen in the first set of interviews conducted at the beginning of patients’ treatment. In contrast, within the first set of interviews, most patients actually spoke of coping by *not* focusing on the future, not dwelling, and preferring to concentrate on what was happening to them at that present time, rather than projecting too far ahead.

Several patients were positive in their expressions of the future. By the end of their treatment, they spoke of beginning to, or at least planning to, resume normal activities, such as going on holiday and being able to eat normally again, returning to work, and most importantly felt that this would help them to put an end to their recent experience and gave them a feeling that they could move on from that. From patients’ accounts of this, it was

clear that focusing on the future and returning to as normal a life as possible was important for helping them to move on from their recent experiences and helping them to regain a sense of control over their lives.

“I’ll recover, I’m looking to the future now. Once I get the results of the scan, I’ll be able to then try and start and live life as normal.” Patient 2

“I’m looking forward [the future]... [my wife] is looking forward to getting a holiday too cos we’ve not had a holiday this year.” Patient 17

“I was desperate to get back to work...I just wanted to get back into the swing of it and I was desperate to do it and I threw myself into it and you know not just teaching but school shows and the committees I’m on.” Patient 22

“As the time span gets longer between today and the future, these feelings will subside and I’ll be back at work before I know it. Patient

24

9.7.2.3 Learning What to Expect

This sub theme arose from patients’ accounts of the emotional impact of undergoing treatment and the need to be prepared for what was going to happen during it. Eight patients identified this sub theme. Whilst this sub theme was identified as the most frequent in relation to patients’ management of the emotional impact, in the second set of interviews, it was noted to be less frequent, with other sub themes occurring more frequently, which may have assumed a greater importance in patients’ self care.

Like in the first set of interviews, patients’ reinforced the importance of preparing for the experience of side effects. However, rather than seeking information, which was the key strategy used in relation to this sub theme at the beginning of patients’ treatment, the accounts in the second set of interviews suggested that patients had learned what to expect

as they progressed through their treatment by recognising a pattern of how and when side effects were likely to affect them, helping them to determine what was normal for them and what wasn't. Their accounts also suggested that this helped them to learn how to take control of their self care decision making. The following examples from the analysed data demonstrate this.

“This tender mouth takes a week and I know the next week, I’m going to have tiredness and the next week, I’m going to feel better. I knew what was coming you know. I had a week of chemo, stopped on the Friday, by the Sunday or Monday I had the sore mouth. I knew what I was expecting and it did fall in that pattern.” Patient 2

“It was usually 3 days when I finished the first week of the chemotherapy each month, that week was no problem I had no sore mouth or anything but it built up in my system obviously...probably finished here on the Friday and a wee bit sore on the Saturday and Sunday...Monday it was pretty sore and then it died down again.”

Patient 10

“I knew that week one was the chemo week, week two I felt pretty bad, week three was recovering and week four I was back to my old self again. It’s been very structured, I’ve known how I’m going to be...it’s followed that pattern you know right throughout it all. I know my own body and I know the reaction that chemo throws up and I knew it would settle itself down.” Patient 24

Like in the first set of interviews, patients spoke of the importance of fellow patients in helping them learn what to expect during their treatment. Being able to share experiences of side effects and self care strategies was an important source of information and reassurance for patients, as suggested in the following examples.

“It helps a lot...sharing your experiences because [patient] and I started at the same time and are finishing at the same time, she’s had the same problems with her skin, same problems with her mouth.” Patient 8

“You can speak to other patients and you can then tell this happened and that happened.” Patient 10

“You learn more by sitting with the patients who are getting treatment. See if you’re sitting here with somebody if you’re on your second treatment and somebody’s sitting on their third and fourth treatment, when you talk and listen to them you hear what’s happening to them and you know what you’re going to get. It’s more [helpful] than the medical profession...people getting treatment all talk amongst themselves...tried this and it’s been successful...tried that and it’s been successful so it’s worth you trying. I’ve found it more beneficial getting friendly with the people who are getting the same type of treatment as you and listening to them, I mean you knew in advance what was going to happen.”

Patient 12

9.7.2.4 Maintaining Normality

This sub theme arose from patients’ accounts of the emotional impact of living with and undergoing treatment for cancer and the strategies that had helped them to manage this impact. In the second set of interviews, conducted at the end of patients’ treatment, patients were able to give detailed accounts of how their treatment had affected their involvement in social life, their work, and their ability to continue with their normal lifestyle. The analysis identified that their meaning of self care as being to maintain normality was still important to patients in the second set of interviews. The following examples from the analysed data demonstrate this.

“You find that the treatment stops the other things that you want to do normally you know family events, grand children...this type of thing [the treatment] does knock a bit out of you.” Patient 1

“I’ve not been on the original employee list and so it makes a difference, it makes a difference to turnover, getting your money in.” Patient 1

“I didn’t have the energy to do very much and I love going on holiday and I haven’t been able to do that...even go to friends to get there it would be too much you know.” Patient 2

In total, six patients identified the importance of maintaining normality as a self care strategy which they carried out in attempting to overcome disruption to their lives, by socialising and spending time with friends, caring for the family, continuing with normal activities where possible and trying not to let the treatment interfere with one’s lifestyle. In their responses, several patients highlighted the importance of being able to just get on with things and live as full a life as possible. These strategies were important not only for their own self care in terms of managing the impact on their own lifestyle but also for maintaining good relationships with their partners and friends, and for cementing their sense of identity and their role within the family unit. These strategies were broadly similar to those employed by patients in the first set of interviews at the beginning of patients’ treatment and were identified as important strategies for maintaining a sense of control over their lives. The following examples highlight some of these strategies.

“I’m always busy anyway. I still am involved in doing sport and involved with the [name of organisation]. You just go and do the things you would normally do or try...just do what you want to do and get on with it.” Patient 1

“I’ve not had a great deal of alteration to my lifestyle since starting treatment...no it’s not interfered greatly. I’ve just lived a normal life through this.” Patient 17

“It didn’t really stop me doing the things I wanted to do. I’m my old self and you know I’m out and about doing things with her [her daughter] and that’s been good for her you know to help her rationalise things I think. I just wanted to be me and be normal and not be obsessed by it [the cancer] and that’s what I did really. I’m still me and that’s important. I like people to see me carrying about my business the way I always did and that for me, helps. I think if you have a family you have to do that...it keeps things on an even keel you know because I don’t want them thinking ‘oh mum’s ill’ you know.” Patient 24

9.7.2.5 Not Dwelling

This sub theme arose from patients’ accounts of the emotional impact of living with and undergoing treatment for cancer and was identified by six patients. Like in the first set of interviews, the idea of not dwelling encompassed a number of strategies such as, taking each day at a time, not looking for additional information to what had already been provided, and focusing on relaxation, distraction and setting yourself goals to relieve anxiety and distress. In contrast to the earlier sub theme of focussing on the future, patients’ use of not dwelling was explained by a perceived lack of control over their situation and the events that they might face in the future.

“I’m trying to stay positive about it. I think I still have these thoughts ‘what if it comes back’ you know. There’s nothing I can do about it, I’ll just need to wait and see what happens.” Patient 2

“Though I’ve had a serious illness and there’s a chance it might return again...I’m not bothered a great deal. [I] just take things as they come.” Patient 17

“There were days when I didn’t think about it you know and it was nice just to get on with a normal life and be able to carry on as if it wasn’t happening. I didn’t tend to access a lot of internet information. I know a lot of patients do but I just felt sometimes you can know too much already and I do know more than I need to know already. People cope in different ways but I just didn’t want to spend my free time on the computer thinking about nothing else but cancer. It’s nice to talk about other things you know...clothes...make up...drivel...I don’t really want to get into in depth conversations about it out of here.” Patient 24

Other patients spoke of finding benefit in identifying ways to relax and distract yourself or set goals so that you were focussed on something other than the cancer, which helped to enhance their perceptions of control.

“I like to plan my day, always have one or two things that I want to get done and it’s something achievable. I think getting yourself into some sort of sequence of normality so that you’re working to certain aims all the time, that helps. Apart from that, if you’ve got something to do, it takes your mind off it. I tend to be fairly single minded, if I’m concentrating on one thing, I’m not thinking about anything else.”

Patient 1

“I went to the Maggie’s Centre and I did a stress course for eight weeks...it was talking and then it was relaxation exercise and one day we went to the park for a walk altogether but not talking and I found that really quite relaxing. When you go into a park with other people

you're chatting and you're not taking in what's about you, the river, the flowers and the people and that was the best part of it." Patient 2

9.7.3 Summary

The findings from the qualitative analysis of the second set of interviews, conducted at the end of patients' treatment, highlighted the range of strategies that patients employed to manage the physical and emotional impact of being diagnosed with, and undergoing treatment for, cancer. The principal physical self care strategies used by patients by the end of their treatment included, treating side effects, principally through medication; adapting to, and compensating for the impact of side effects; and relying on the expertise and experience of health professionals. This reliance seemed to be based on patients' perceptions that they did not expect themselves to be involved in self care, and did not perceive themselves to be knowledgeable or experienced enough to take charge of managing their side effects ('health professionals know best').

Emotional self care strategies carried out by patients towards the end of their treatment included, focusing on the future and trying to move on from their experience of treatment; learning what to expect, particularly, learning to identify the pattern of how and when side effects normally affected them; maintaining a sense of normality; and not dwelling on the thought of having cancer and finding ways to distract oneself or relax.

9.8 Perceptions of Control

9.8.1 Degree of Control

The degree of control that patients perceived themselves to have emerged in both the first and second sets of interviews, from questions such as, "how much control do you feel you have at the moment", "how much control do you feel you have over managing the impact of your treatment" and "how important is it that you have a degree of control over the impact

of your treatment’. Two sub themes relating to degree of control were identified within this theme (shown in Table 9.7).

| Key themes | Sub themes | No of patients who identified sub theme |
|-------------------|----------------------------------|---|
| Degree of Control | High degree of control (9.8.1.1) | n=4 |
| | Low degree of control (9.8.1.2) | n=5 |

Table 9.7 Themes and sub themes relating to ‘degree of control’

As the following sections demonstrate, there were some notable differences in the transcripts between the degree of control that patients perceived themselves to have. For example, there were some who perceived that they had a great deal of control during their treatment and could influence their experiences through their self care. On the other hand, there were others who perceived themselves to have little control during their treatment and little influence over their symptom experiences by being actively involved in their self care. These distinctions were evident from their responses to questions in the interviews such as, ‘how much control do you feel you have at the moment?’, ‘how much control do you feel you have over your self care?’ and ‘how important is it for you to feel that you have some control?’. The following sections present some examples from the qualitative data to illustrate these perceptions.

9.8.1.1 Higher Degree of Control

This sub theme arose from patients’ accounts of their perceptions of having a high degree of control over managing the impact of their treatment and their accounts of the importance of maintaining a sense of control during their treatment. Therefore, this sub theme became known as ‘high degree of control’ and was described by four patients (in their first and second interviews). The following quotes are examples from the analysed data of these perceptions.

“Just having some sort of goal to aim at [is important]...and the great thing is that all these things [self care activities] are within your own control. You do have a level of control and I think whatever you do, being positive about it helps and there are things that you can always do yourself to help.” Patient 1, Interview 2

“I’ve always been a strong person...I’ve controlled it [the treatment effects] right from the start you know...that’s the name of the game, you just cannae lie back...I’m taking control of it.” Patient 12, Interview 2

“I’m quite a strong person and I’m quite sensible...if I’d had to constantly phone up and ask advice about things I think I’d have felt...it’d just have made me feel that someone else was running my life if you know what I mean...to constantly have self doubt and have to phone up and seek help from the GP, that would have just driven it home what was wrong with me.” Patient 24, Interview 2

There was also evidence within these patients’ transcripts which demonstrates their perception that they had a high degree of control during their treatment. For example, in both the first and second sets of interviews patients with higher perceptions of control spoke of being able to influence their side effect experiences through their self care, and spoke of their desire and importance of being involved in their own self care and the ways in which they acted in order to help them manage the impact of their treatment and maintain a sense of control during their treatment. The following quotes are examples from the analysed data illustrating these perceptions.

“I definitely [like to] get back to doing something physical and normally what I’ll do is work till I’m knackered and then stop, give it a couple of minutes and then I’ll start again. You know I’ve seen me where I’m out and five minutes and I’m tired but I’ll work at it you

*know...the more effort I put in, the quicker I bounce back.” Patient 1,
Interview 2*

*“I made up my mind...I was going to try and take some control over
things you know I wasn’t going to leave it in anybody else’s hands...I
was going to take control over what I was doing and what they [hospital
staff] were doing and I think that has helped me a lot because I was able
to take control.” Patient 12, Interview 2*

*“I was able to cope with that easily [the potential for side effects] you
know cos I know I’m taking part in it and coping...any diarrhoea, I’ll
take that Loperamide...it stops the diarrhoea.” Patient 31, Interview 1*

9.8.1.2 Lower Degree of Control

This sub theme arose from patients’ accounts of their perceptions of having a low degree of control over managing the impact of their treatment. Their accounts also revealed that they did not expect to take control over managing the impact of their treatment nor believe that having a sense of control was important to them during their treatment. Therefore, this sub theme became known as ‘low degree of control’ and was described by five patients (in their first and second interviews). The following quotes from the analysed data are examples of these perceptions.

*“I think the fact I’ve taken cancer, I’ll always have it on my mind that I
might take secondary cancer and that can be quite serious but you know
...em...take one day at a time I suppose and whatever’s for you you
know...there’s nothing I can do about it, I’ll just need to wait and see
what happens.” Patient 2, Interview 2*

*“I don’t think I’ve got control over it [side effects]...the nurses and
doctors were in charge of what was happening...no I’ve not had a great
deal of control.” Patient 17, Interview 2*

“There’s a feeling that sometimes you can’t do anything about the side effects....and I don’t feel totally in control of some of the things...you know I can do my best to help with it but I’m aware that things could flare up and so no, I don’t have total control over it.” Patient 22, Interview 1

There was evidence within these patients’ transcripts to reinforce their perceptions of a low degree of control. The following quotes suggested that in this study patients with lower perceptions of control were more likely to believe that they had little influence over their side effect experiences and were more likely to perceive that they were not experienced enough to carry out effective self care. They were also less likely to perceive that self care was important and less likely to expect to play a role in their self care, particularly preventative self care, and predominantly chose to rely on health professionals, and also doubted the efficacy of their self care. The following quotes also suggested that patients with lower perceptions of control also perceived that they would use fewer self care strategies, principally relying on the use of medications and input from health professionals.

“I don’t think I was actually looking for any information...I was quite happy to do what they said and not look elsewhere...because they know best.” Patient 2, Interview 2

“I’ll cope with them [the side effects] when they appear...if they appear...I don’t need to [seek information]...I’ve got it [information]...plus the district nurses are on call if there’s anything. I’ve got all their phone numbers and can probably get one at a moment’s notice you know.” Patient 17, Interview 1

“At no point did I feel in control of it [the side effects]...I knew I could help with it but I knew I couldn’t stop the symptoms and prevent them and I really felt quite down and depressed about it. I did all the

recommended things and it certainly helped to alleviate some of the symptoms but no, it didn't make me feel in control and no, it didn't make me feel I could prevent anything.” Patient 22, Interview 2

9.8.2 Factors Contributing to Perceptions of Control

The theme, factors contributing to perceptions of control, emerged in both the first and second sets of interviews from exploratory follow up questions to patients' responses to the initial questions asking how much control patients perceived themselves to have over managing the impact of their treatment and the importance of having a sense of control. For example, these involved using questions such as “why do you think that” and “why do you feel that way”. Two sub themes relating to factors influencing perception of control were identified within this theme (shown in Table 9.8).

| Key themes | Sub themes | No of patients who identified sub theme |
|---------------------------------------|---|--|
| Factors influencing degree of control | Factors contributing to perceptions of high control (9.8.2.1) | n=4 |
| | Factors contributing to perceptions of low control (9.8.2.2) | n=5 |

Table 9.8 Themes and sub themes relating to ‘factors influencing degree of control’

9.8.2.1 Factors Contributing to Perceptions of High Control

There were common themes in the analysed data from the first and second sets of interviews of the patients who perceived themselves as having a high degree of control. In particular, patients believed in the purpose and efficacy of the chemotherapy treatment, the efficacy of medications used to help manage side effects and their perceptions of treatment-related side effects as being influenced by one's actions, being temporary, being nothing more than an inconvenience or being a small price to pay. The following quotes from the analysed data are examples of these perceptions.

“The treatment’s there to try and prevent...to save my life you know...it’s got to be done if you want to try and survive...eh...it’s got to be done.” Patient 12, Interview1

“I’ve got over other things that have got me down you know and it’s a small price to pay to live you know and I’ll manage fine...it’s only a temporary thing that’ll happen, I’ll be fine.” Patient 24, Interview 1

“I felt that I was coping with the situation and what I was doing was the right things and it was preventing situations from getting out of hand and when I felt that I felt very confident because I said well I’ve got the right dose and I’ve got the right tools to stop it getting out of hand and I felt quite confident and good because I’ve got them [the medications] there.” Patient 31, Interview 1

In the latter interviews, further possible explanations were revealed as being perceptions related to the treatment not having had as great an impact on their lives as expected. The analysed data suggested that patients felt they had been able to retain a sense of normality and continue with their normal routines and activities and that the treatment-related side effects had been not as severe as they had been warned about and that they had felt able to cope well with these. Furthermore, patients spoke of being able to cope with the side effects because they had learned how the pattern of side effects typically affected them, because the side effects had remained similar throughout the duration of their treatment and because they had found ways to adapt to and compensate for these. Another possible explanation was revealed as being patients’ access to self care information through fellow patients. The following quotes are examples of these perceptions from the analysed data.

“I’ve found it more beneficial getting friendly with the people who are getting the same type of treatment that you’re getting and listening to them. I mean you knew in advance what was going to happen when you

talk to other people. They've all got the same signs, the same problems and I found that more beneficial than anything else.” Patient 12, Interview 2

“I can't honestly say that it felt dreadful...it was very bearable...because the side effects weren't too drastic, it didn't really stop me doing the things I wanted to. The side effects have all been minimal, they've been mildly irritating for some of them but they've all been bearable...I've managed to cope with them all.” Patient 24, Interview 2

“It's been very structured you know I've known each week how I'm going to be and it's sort of followed that pattern you know right through it all.” Patient 24, Interview 2

9.8.2.2 Factors Contributing to Perceptions of Low Control

There were common themes in the analysed data from the first and second sets of interviews of the patients who perceived themselves as having a low degree of control. In particular, patients believed that they were not experienced enough to carry out effective self care, didn't know what to expect from their treatment, for example, in terms of its duration or its side effects or whether these effects were or were not related to the treatment, and chose to rely on health professionals which they often referred to this as their key self care strategy when speaking of managing the impact of their treatment. Furthermore, patients referred to not being able to live like they normally would and spoke of the treatment-related side effects as being something which could not be influenced through their own self care and the use of medications and which simply had to be endured as part of the treatment process. The following quotes are examples of these perceptions from the analysed data.

“I think...eh...phoning someone would be a secondary [measure]...eh...first bench to climb would be trying medication first and if that didn’t work then obviously I might get something wrong again and I’d get in touch with somebody else a wee bit more experienced. They’re [health professionals] people with experience in situations like that.” Patient 11, Interview 1

“It’s a difficult position to be in with side effects...it’s difficult to tell if things are side effects or whether there is anything else wrong with me. It won’t all be side effects, people have aches and pains and minor ailments and things...but you know at the moment I can see that my GP is really worried about interfering in anything you know and she doesn’t really know.” Patient 22, Interview 1

“Nobody seems to be able to give you completely specific information about the side effects and I think that is what is difficult. They tell you what side effects you may experience...okay you experience some of these symptoms and you do the things that they give you to help...you do your own self care things but whether they actually help or not or whether after five days your mouth just gets better...I don’t know. I mean I have no control over what the next side effect will be and a lot of the things that you do to try and prevent it don’t prevent it happening.”

Patient 22, Interview 1

In the latter interviews, patients continued to speak of their lack of experience to self care and their reliance on health professionals and medications, their inability to live normally and having to restrict their normal activities and routines as well as the perception that the treatment-related side effects simply had to be endured as opposed to managed, that they did not believe in the efficacy of their self care and had issues related to body image and adaptation. There were also some further possible explanations for patients’ perceptions of

a lack of control identified from the second set of interviews. In particular, patients spoke of the anxiety that they experienced because the process of administering the chemotherapy involved needles and the implications of this and not having a full explanation given to them about what they could expect during treatment. They also spoke of experiencing severe or fluctuating side effects from month to month, or experiencing different side effects towards the end of treatment for which people felt unprepared for, having never experienced them before. The following quotes are examples of these perceptions from the analysed data.

“I just got my chemo and that was me. Nobody really...I thought the [nurse specialist]... she would tell me the side effects and what to do and all that but she didn't. I didn't see her. I felt, I don't know,...a wee bit out on my own but I really thought that when I came for chemo that somebody would take me into a room and sort of explain it all to me you know.” Patient 2, Interview 2

“They [the side effects] varied from month to month...one of the things would be particularly bad one month and then another month it'd be something else...you couldn't always be prepared you know.” Patient 22, Interview 2

9.9 Overall Summary of the Qualitative Analysis

The findings from the analysed data from the semi structured interviews revealed several key findings in relation to patients' perceptions and experiences of self care and their perceptions of control during their six month course of chemotherapy treatment. The analysis identified that patients ascribed different meanings to their self care and made a distinction between the self care activities that they carried out to manage the physical and emotional impact of their treatment. In particular, patients spoke of self care as being about

limiting the impact of treatment, an attempt to 'be normal' and 'stay positive' and was a process which involved a degree of problem solving and using your own judgement.

The analysis revealed that a range of physical and emotional self care activities were carried out by patients, the use of which appeared to change slightly between the beginning and end of treatment. Overall, similar self care strategies were used by patients at both the beginning and end of their treatment, particularly treating physical side effects using medications and relying on health professionals, adapting to and compensating for the physical impact of their treatment, learning what to expect from the treatment process, maintaining a sense of normality in one's life, rationalising and comparing the impact of their diagnosis and treatment, and not dwelling on this impact and their concerns for the future. There was, however, evidence that towards the end of their treatment, patients spoke of using a greater range of 'adaptive' strategies, particularly aimed at managing their dietary needs and eating patterns in order to alleviate side effects, than they had at the beginning of their treatment.

By the end of their treatment patients also appeared to more frequently 'rationalise and compare' their situation to others around them than they had at the beginning of their treatment, where learning what to expect from the treatment process had been their predominant emotional self care strategy. In particular, towards the end of their treatment many patients rationalised that in reflecting upon their experience of undergoing treatment they perceived themselves to be lucky, to have experienced few problems with treatment-related side effects and had coped well throughout the duration of their treatment as opposed to rationalising that they had to undergo treatment for a better chance of survival as they had done at the beginning of their treatment. Learning what to expect from the treatment process was still an important self care strategy used towards the end of treatment, however, the particular strategies that they used relating to this theme differed between the beginning and end of their treatment. This was identified by many patients as

rather than seeking information about their treatment as they had done so at the beginning of their treatment, they spoke of learning what to expect through identifying patterns of how side effects normally affected them and the impact that these had on their lives.

Furthermore, at the beginning of treatment, patients spoke of their desire to avoid focusing on the future whilst towards the end of their treatment they spoke of looking towards the future in a positive light and subsequently this became a key self care strategy for patients. Finally, the analysis revealed that throughout the duration of their treatment, patients continued to show a strong degree of reliance on health professionals, throughout the duration of their treatment, expecting them to be the ones who managed any side effects that the patient experienced.

In relation to patients' perceptions of control, the analysis of the interviews suggested that some of the patients in the study perceived themselves to have a high degree of control during their treatment. The data suggests that these patients seemed more likely to perceive themselves as being able to influence their side effect experiences and have control over their own self care, were more interested in self care and believed it was more important, and were more likely to act in ways to maintain or regain a sense of control during their treatment. Others, however, perceived themselves to have a low degree of control during their treatment. The data suggested that these patients were less likely to perceive that they could influence their side effect experiences and take control over self care, were more likely to perceive that they were not experienced enough to carry out self care, less likely to perceive self care as being important and tended to rely on one or two specific self care strategies (rather than a range of self care strategies) namely, relying on the use of medications and relying on the expertise and experience of health professionals.

Analysis of the first and second sets of interviews were particularly valuable for explaining the degree of control that patients perceived themselves to have and the factors which may

influence these perceptions. The data suggests that perceptions of control may be influenced by factors such as, patients' perceptions and experiences of treatment-related side effects and their impact, issues related to body image and adaptation, their perceptions about the purpose and efficacy of undergoing chemotherapy treatment, access to self care information, patients' perceptions regarding their ability to undertake self care and the perceived efficacy of their self care efforts. These findings are valuable since little previous work has focussed on the factors that influence patients' perceptions of control during a course of chemotherapy treatment. Furthermore, analysis of both the first and second sets of interviews revealed that patients' perceived degree of control appeared to differ little between the beginning and end of their treatment and thus, remained relatively unchanged across the six month period in which they received their treatment.

The following chapter (Chapter 10) focuses on the findings from the quantitative analysis of patients' perceptions and experiences of being involved in self care, and their perceptions of control and self efficacy. In Chapter 11, both the qualitative and quantitative findings are merged in order to interpret the findings in relation to each other and to offer a fuller understanding of patients' involvement in self care, and the association of their perceptions of control and self efficacy.

Chapter 10 Quantitative Analysis

10.1 Introduction

The following chapter presents the findings from the quantitative analysis of the questionnaires and self care diaries which focussed on identifying changes in, and associations between, the degree of self care carried out by patients and their perceptions of control and self efficacy. In particular, the chapter also sets out to test whether the study findings support the exploratory hypotheses of the study which proposed that the degree of self care carried out by patients and their perceptions of control and self efficacy would increase from the beginning to end of their six month course of chemotherapy treatment, and that patients who perceived themselves to have a high level of control and self efficacy would carry out a greater degree of self care.

The chapter begins by describing patients' perceptions of the degree of self care, and the specific types of self care activities, that they carried out at the beginning (T1, cycle 1), middle (T2, cycle 3) and end (T3, cycle 6) of their chemotherapy treatment. Patients' perceptions of control and self efficacy at the beginning (T1), middle (T2) and end (T3) of their treatment are then reported. These descriptions presenting the median and range of scores were important for highlighting whether patients' perceptions of these variables had changed during the course of their treatment. The median and range are considered to be more appropriate descriptives when using non parametric analyses because these are distribution free, hence they do not assume normal distribution (Brace et al, 2006), and were used in the current study because of its relatively smaller sample size. The significance of any changes in the variables between each time point were analysed using the non parametric Friedman's ANOVA statistical test. In section 10.5, the association between the degree of self care carried out by patients and their perceptions of control and self efficacy was analysed using the non parametric Spearman's Rho statistical test of association in order to determine whether patients' degree of involvement in self care was associated with their perceptions of control and self efficacy.

10.2 Perceptions of Self Care

Two subscales of the self care diary (an example of a page from the diary is shown in Appendix 4) were included in the analysis. These were i) the degree of self care carried out, and ii) the specific types of self care activities that were carried out by patients, at all three time points. It was important to determine quantitatively the changes in the degree of self care carried out by patients but also, in order to understand patients' involvement in self care further, to determine quantitatively the changes in the specific types of self care activities that they carried out. Patients collected data in the self care diary daily for 28 days at each of the data collection time points, therefore, the possible range of values on both subscales for each time point was 0-28. Both subscales are discussed separately in the following sections (10.2.1 and 10.2.2).

10.2.1 Degree of Self Care Carried Out

In order to compare the degree of self care carried out by patients between time points, the data were summed to provide the total number of days on which patients had reported carrying out self care (possible range 0-28). The data in Table 10.1 describes the median and range of values (representing number of days) on which patients reported that they had carried out self care for each time point. Values have been rounded to one decimal place.

| | Time point | Median | Range |
|-----------------------|---------------------|---------------|--------------|
| Self Care Carried Out | Cycle 1 (T1) (n=24) | 27.5 | 7.0-28.0 |
| | Cycle 3 (T2) (n=24) | 28.0 | 4.0-28.0 |
| | Cycle 6 (T3) (n=24) | 28.0 | 7.0-28.0 |

Table 10.1: Median and range of values (representing number of days) reported by the sample for degree of involvement in self care at T1, T2 and T3

The values in Table 10.1 indicate that the patients in this sample carried out a high degree of self care at each time point, across their six month course of chemotherapy treatment. This was despite reporting having had no symptoms on several days, suggesting that they may also have attempted to undertake preventative self care. The median values show a slight increase in the degree of self care being carried out by patients from the beginning to

the middle of their treatment (T2) and it also appeared to remain at this level at the end of patients' treatment (T3). Using the Friedman's ANOVA test on patients who completed and returned data at all three time points (n=24), the changes were identified as being significant (at $p < 0.05$) ($\chi^2 = 6.615$, $p = 0.04$). Post-hoc non parametric Wilcoxon Signed Rank Tests were employed to identify that there was a significant increase seen in the degree of self care carried between the beginning (T1) and middle (T2) of patients' treatment ($z = 2.074$, N-Ties=13, $p = 0.04$) and a significant decrease between the middle (T2) and end (T3) of patients' treatment ($z = 2.008$, Ties=12, $p = 0.05$). These results may appear surprising given that there were little changes seen in the median values between each of the three time points, however, inspection of the mean values (23.1-T1, 25.5-T2, 23.2-T3) reflects this peak in the middle (T2) of patients' treatment. The degree of self care carried out by patients, however, although changed over time, did not increase incrementally over the three time points as was hypothesised at the beginning of the study.

In order to obtain a more detailed representation of patients' involvement in self care, it was useful to identify the specific self care activities that patients carried out at each time point. Furthermore, because of the longitudinal design of the study, patterns in any changes in the use of these activities from the beginning to end of patients treatment could be determined. The analysis of these are considered in the following section.

10.2.2 Pattern of Self Care Activities Carried Out

The data in Table 10.2 illustrates the list of self care activities that were provided to patients in the self care diary and, for the purposes of data analysis, their corresponding codes. As noted in Chapter 6, the list of self care activities contained within the self care diary was devised following a review of relevant literature and validation by clinical staff at the clinical site where the research was conducted.

| Physical Side Effect | Self Care Activities |
|----------------------|---|
| Diarrhoea | D1: Watch for any changes with your bowels |
| | D2: Take anti-diarrhoea tablets |
| | D3: Maintain personal hygiene |
| | D4: Watch or change your diet (e.g. increased intake of high fibre foods) |
| | D5: Drink plenty fluids |
| Nausea/Vomiting | NV1: Take anti-sickness tablets |
| | NV2: Watch or change your diet (e.g. eat small and frequent meals) |
| | NV3: Relaxation and distraction exercises |
| Mucositis | M1: Watch for any changes with your mouth |
| | M2: Use regular mouthwashes |
| | M3: Clean teeth regularly |
| | M4: Use a throat spray or lozenges |
| | M5: Drink plenty fluids |
| | M6: Watch or change your diet (e.g. avoid hard or crunchy foods) |
| Fatigue | F1: Stop and rest when needed |
| | F2: Gently exercise when you can |
| | F3: Eat a healthy, balanced diet |

Table 10.2: List of specific self care activities for each side effect

As in the previous analysis on the degree of self care carried out by patients, to compare the types of self care activities carried out by patients between time points, the data were summed to provide the total number of days on which patients had carried out each specific activity (possible range 0-28). The data in Tables 10.3-10.6 describe the median and range of values (representing number of days) for the degree to which each specific self care activity was carried out (for the symptoms of diarrhoea, nausea and vomiting, mucositis, and fatigue) at each time point. Values have been rounded to one decimal place.

| Time point | | D1 | D2 | D3 | D4 | D5 |
|------------------------|--------|----------|----------|----------|----------|----------|
| Cycle 1 (T1) (n=24) | Median | 14.0 | 1.0 | 20.5 | 4.0 | 20.0 |
| | Range | 0.0-28.0 | 0.0-12.0 | 0.0-28.0 | 0.0-28.0 | 0.0-28.0 |
| Cycle 3 (T2) (n=24) | Median | 26.5 | 1.0 | 27.0 | 4.0 | 27.0 |
| | Range | 0.0-28.0 | 0.0-12.0 | 0.0-28.0 | 0.0-28.0 | 0.0-28.0 |
| Cycle 6 (T3) (n=24) | Median | 20.0 | 1.0 | 26.0 | 9.0 | 26.0 |
| | Range | 0.0-28.0 | 0.0-17.0 | 0.0-28.0 | 0.0-28.0 | 0.0-28.0 |

Table 10.3: Median and range of values (representing number of days) reported by the sample for each specific self care activity for managing diarrhoea at T1, T2 and T3

| Time point | | NV1 | NV2 | NV3 |
|---------------------|--------|----------|----------|----------|
| Cycle 1 (T1) (n=24) | Median | 1.5 | 3.0 | 5.0 |
| | Range | 0.0-24.0 | 0.0-26.0 | 0.0-28.0 |
| Cycle 3 (T2) (n=24) | Median | 2.5 | 1.0 | 3.0 |
| | Range | 0.0-28.0 | 0.0-27.0 | 0.0-28.0 |
| Cycle 6 (T3) (n=24) | Median | 1.5 | 6.0 | 4.5 |
| | Range | 0.0-24.0 | 0.0-28.0 | 0.0-28.0 |

Table 10.4: Median and range of values (representing number of days) reported by the sample for each specific self care activity for managing nausea and vomiting at T1, T2 and T3

| Time point | | M1 | M2 | M3 | M4 | M5 | M6 |
|---------------------|--------|----------|----------|----------|----------|----------|----------|
| Cycle 1 (T1) (n=24) | Median | 14.5 | 8.5 | 25.5 | 1.5 | 24.5 | 7.0 |
| | Range | 0.0-28.0 | 0.0-28.0 | 0.0-28.0 | 0.0-19.0 | 3.0-25.0 | 0.0-28.0 |
| Cycle 3 (T2) (n=24) | Median | 23.0 | 13.5 | 27.0 | 1.0 | 27.0 | 8.5 |
| | Range | 0.0-28.0 | 0.0-28.0 | 0.0-28.0 | 0.0-28.0 | 0.0-28.0 | 0.0-28.0 |
| Cycle 6 (T3) (n=24) | Median | 13.5 | 11.0 | 26.5 | 1.0 | 27.0 | 7.0 |
| | Range | 0.0-28.0 | 0.0-28.0 | 0.0-28.0 | 0.0-28.0 | 0.0-28.0 | 0.0-28.0 |

Table 10.5: Median and range of values (representing number of days) reported by the sample for each specific self care activity for managing mucositis at T1, T2 and T3

| Time point | | F1 | F2 | F3 |
|---------------------|--------|----------|----------|----------|
| Cycle 1 (T1) (n=24) | Median | 24.5 | 20.5 | 23.5 |
| | Range | 0.0-28.0 | 0.0-28.0 | 0.0-28.0 |
| Cycle 3 (T2) (n=24) | Median | 27.5 | 27.0 | 26.5 |
| | Range | 2.0-26.0 | 0.0-28.0 | 0.0-28.0 |
| Cycle 6 (T3) (n=24) | Median | 24.5 | 25.0 | 22.5 |
| | Range | 2.0-26.0 | 0.0-28.0 | 0.0-28.0 |

Table 10.6: Median and range of values (representing number of days) reported by the sample for each specific self care activity for managing fatigue at T1, T2 and T3

The median values in these tables indicate that patients' use of specific self care activities for treating diarrhoea, nausea and vomiting, mucositis and fatigue was fairly consistent from the beginning to the end of their treatment. There seemed, however, to be some specific self care activities that were carried out to a lesser extent than others. These activities included, taking medications for treating diarrhoea and nausea and vomiting, changing diet in order to treat diarrhoea, and using mouthwashes, throat sprays and lozenges to treat mucositis. On the other hand, activities that were more related to maintaining one's general health and well being, and perhaps part of peoples' daily activities to begin with, and not attributable to the managing the effects of cancer treatment for example, maintaining personal hygiene, cleaning teeth, and eating a healthy, balanced diet seemed to be carried out to greater extent.

The quantitative analysis of the specific self care activities carried out in the self care diary revealed that patients' use of many of the activities appeared to peak in the middle of their treatment (T2), reflecting the peak seen in the degree of self care carried out in the middle of patients' treatment (T2) as noted in section 10.2.1. The data in Table 10.7 demonstrates the median values and the results from the statistical analysis of changes over time in each of the self care strategies between the beginning, middle and end of treatment, using the Friedman's ANOVA test on patients who completed and returned data at all three time points (n=24).

| | | Cycle 1 (T1) | Cycle 3 (T2) | Cycle 6 (T3) | χ^2 | p |
|-------------------|-----|--------------|--------------|--------------|----------|-------|
| Diarrhoea | D1 | 14.0 | 26.5 | 20.0 | 3.459 | 0.18 |
| | D2 | 1.0 | 1.0 | 1.0 | 2.941 | 0.23 |
| | D3 | 20.5 | 27.0 | 26.0 | 2.962 | 0.23 |
| | D4 | 4.0 | 4.0 | 9.0 | 2.732 | 0.26 |
| | D5 | 20.0 | 27.0 | 26.0 | 1.614 | 0.45 |
| Nausea & Vomiting | NV1 | 1.5 | 2.5 | 1.5 | 2.459 | 0.29 |
| | NV2 | 3.0 | 1.0 | 6.0 | 0.243 | 0.89 |
| | NV3 | 5.0 | 3.0 | 4.5 | 1.463 | 0.48 |
| Mucositis | M1 | 14.5 | 23.0 | 13.5 | 2.775 | 0.25 |
| | M2 | 8.5 | 13.5 | 11.0 | 3.256 | 0.20 |
| | M3 | 25.5 | 27.0 | 26.5 | 0.110 | 0.95 |
| | M4 | 1.5 | 1.0 | 1.0 | 0.098 | 0.95 |
| | M5 | 24.5 | 27.0 | 27.0 | 1.658 | 0.44 |
| | M6 | 7.0 | 8.5 | 7.0 | 3.390 | 0.18 |
| Fatigue | F1 | 24.5 | 27.5 | 24.5 | 6.099 | 0.05* |
| | F2 | 20.5 | 27.0 | 25.0 | 3.263 | 0.20 |
| | F3 | 23.5 | 26.5 | 22.5 | 2.304 | 0.32 |

*significant at $p < 0.05$

Table 10.7: Median values and statistical analysis for changes in the use of specific self care activities across the three time points (n=24)

The data in Table 10.7 demonstrates that there were no statistically significant changes identified in use of the majority of the specific self care activities over time, with the exception of the activity of stopping and resting (indicated as F1 in Table 10.7) which was identified as just being significant ($\chi^2=6.099$, $p=0.05$) at the level of $p < 0.05$. Further statistical analysis conducted on this self care activity using a post hoc non parametric Wilcoxon Signed Rank Test, identified that there was a significant increase in the use of that particular fatigue-related self care strategy between the beginning (T1) and middle (T2) of patients' treatment ($z=2.180$, $N\text{-Ties}=18$, $p=0.03$), as in the increase between T1 and T2 seen in the degree of self care carried out as described in section 10.2.1. There were no

differences identified in any of the other post hoc comparisons. It is also important to acknowledge, however, that this finding may be due to chance, given the number of analyses conducted (n=17). Finally, as with the previous findings, although patients' use of this fatigue-related strategy, namely stopping and resting, appeared to peak at T2, their use of it did not increase across each of the three time points as was initially hypothesised.

The individual self care activities carried out by patients for each side effect were also computed into a new variable to give a composite score for the degree of self care carried out for each side effect at each time point. The data in Table 10.8 demonstrates the median values and the results from the statistical analysis of changes in the use of self care for managing each side effect between the beginning, middle and end of treatment, using the Friedman's ANOVA test on patients who completed and returned data at all three time points (n=24).

| Side effect that self care was carried out for | Cycle 1 (T1) | Cycle 3 (T2) | Cycle 6 (T3) | χ^2 | p |
|--|--------------|--------------|--------------|----------|-------|
| Diarrhoea | 71.0 | 85.0 | 83.5 | 4.622 | 0.10 |
| Nausea & Vomiting | 11.5 | 15.5 | 14.0 | 0.494 | 0.78 |
| Mucositis | 83.0 | 97.5 | 85.0 | 0.747 | 0.69 |
| Fatigue | 62.0 | 80.5 | 65.5 | 6.500 | 0.04* |

*significant at p<0.05

Table 10.8: Median values and statistical analysis for changes in the use of self care activities during patients' treatment (n=24)

The results from this analysis demonstrate that there were no statistically significant changes identified across the data collection points for the majority of self care activities carried out for each specific side effect, with the exception of self care carried out to manage fatigue ($\chi^2=6.500$, $p=0.04$) with fatigue scores appearing to peak at T2. Post-hoc statistical analyses using the Wilcoxon Signed Rank Test identified that the significant increase occurred between the beginning (T1) and middle (T2) of patients' treatment ($z=2.295$, $N\text{-Ties}=21$, $p=0.02$) with no differences identified in any of the other post hoc comparisons. This trend was similar to the findings seen in the degree of self care carried out, as described in section 10.2.1, and in the use of the specific self care activity of

stopping and resting, as described in section 10.2.2, i.e. a peak seen at T2, however, did not increase incrementally across each of the three time points as was hypothesised.

In summarising the analysis of the degree and patterns of self care carried out by patients during the study, section 10.2.1 demonstrated evidence of a statistically significant change in the degree of self care carried out, peaking between the beginning and middle of patients' six month course of chemotherapy treatment. Similarly, section 10.2.2 demonstrated evidence of a statistically significant change in the use self care activities for managing the side effect of fatigue, particularly patients' use of stopping and resting as a principal self care activity. Again this change occurred between the beginning and middle of patients' six month course of chemotherapy treatment. The results from this analysis, however, should be interpreted with caution owing to the relatively small sample size and the risk that these findings could be due to chance given the number of analyses that were performed. Furthermore, although the degree of self care carried out and patients' use of 'stopping and resting' to manage fatigue appeared to peak in the middle of their treatment, these variables did not increase incrementally over time as was initially hypothesised.

10.3 Patients' Perceptions of Control

Three subscales of the IPQ-R (shown in Appendix 3) were included in the final analysis. These included 'personal control', 'treatment control', and 'emotional representations', since it was hypothesised that perceptions of control would increase over time and that these may change because of experiences with their treatment. The 'emotional representations' subscale was included in this analysis since patients' emotional reactions towards their diagnosis and treatment may influence their perceptions of control and their perceptions towards being involved in their self care. It was initially intended that the 'consequences' subscale would also be included in the analysis, however, as noted in Chapter 8, this subscale was excluded since it demonstrated poor internal reliability on two

out of the three data collection time points. Table 10.9 demonstrates the items that comprised each of the subscales that were included in the final analysis.

| Subscale | Items | Number of items |
|---------------------------|-----------|-----------------|
| Personal Control | IP12-IP17 | 6 |
| Treatment Control | IP19-IP23 | 5 |
| Emotional Representations | IP33-IP38 | 6 |

Table 10.9: Selected subscales of IPQ-R for analysis, items and number of items within each subscale

In accordance with the scoring manual for the IPQ-R (Moss Morris et al, 2002), scores for all of the items on each subscale were summed to derive a value for the individual subscales at each time point. Table 10.10 highlights the range of possible scores for each subscale and the items that were scored in increasing (1=strongly disagree to 5=strongly agree) or reverse order (1=strongly agree to 5=strongly disagree).

| Subscale | Possible range | Increasing order scoring | Reverse order scoring |
|---------------------------|----------------|------------------------------|-----------------------|
| Personal Control | 6-30 | IP12, IP13, IP14, IP16 | IP15, IP17 |
| Treatment Control | 5-25 | IP20, IP21, IP22 | IP19, IP23 |
| Emotional Representations | 6-30 | IP33, IP34, IP35, IP37, IP38 | IP36 |

Table 10.10: Possible range of scores for each subscale and the items that were scored in increasing or reverse order

Higher scores on the *personal* and *treatment control* subscales represent positive beliefs about the person's ability to control the effects of the illness and its treatments. Higher scores on the *emotional representations* subscale represent strong emotional reactions to the effects of the illness and its treatments. The values shown in Table 10.11 describe the median and range of values reported by the sample for each subscale at each data collection time point. Values have been rounded to one decimal place.

| Subscale | Time point | Median | Range |
|---------------------------|---------------------|-------------------|-----------|
| Personal Control | Cycle 1 (T1) (n=24) | 22.0 (18.0/30.0) | 18.0-30.0 |
| | Cycle 3 (T2) (n=24) | 21.5 (12.0/25.0) | 12.0-25.0 |
| | Cycle 6 (T3) (n=24) | 21.0 (12.0)/26.0) | 12.0-26.0 |
| Treatment Control | Cycle 1 (T1) (n=24) | 20.0 (15.0/25.0) | 15.0-25.0 |
| | Cycle 3 (T2) (n=24) | 20.0 (17.0/25.0) | 17.0-25.0 |
| | Cycle 6 (T3) (n=24) | 19.5 (15.0/24.0) | 15.0-24.0 |
| Emotional Representations | Cycle 1 (T1) (n=24) | 18.0 (9.0/26.0) | 9.0-26.0 |
| | Cycle 3 (T2) (n=24) | 17.5 (7.0)/24.0) | 7.0-24.0 |
| | Cycle 6 (T3) (n=24) | 18.5 (12.0/24.0) | 12.0-24.0 |

Table 10.11: Median and range of values reported by the sample for each control-related subscale at T1, T2 and T3

The values shown in Table 10.11 demonstrate that although the median scores for perceptions of personal and treatment control did not fluctuate greatly between time points. Using the Friedman's ANOVA test on patients who completed and returned data at all three time points (n=24), however, the reduction seen in personal control between the three time points were not statistically significant ($\chi^2=0.023$, $p=0.99$).

Although there was little fluctuation in the median scores for treatment control, the analyses found that there was a statistically significant reduction in perceptions of treatment control ($\chi^2=7.649$, $p=0.02$). Post-hoc statistical analyses using the Wilcoxon Signed Rank Test identified that this reduction occurred between the scores seen at the beginning (T1) and end (T3) of patients' treatment ($z=2.228$, $N\text{-Ties}=20$, $p=0.03$), with no further differences identified in any of the other post hoc comparisons. These results may appear surprising given that there were little changes seen in the median values between each of the three time points, however, inspection of the mean values (20.2-T1, 20.1-T2, 19.1-T3) reflects the slight reduction in perceptions of treatment control between the beginning and end of patients' treatment. The significant reduction seen in patient's perceptions of treatment control between the beginning and end of treatment, however, opposes the initial hypothesis, namely that perceptions of control would increase incrementally across the three time points.

The median scores shown in Table 10.11 for emotional representations also demonstrate little fluctuation between time points, although the scores decreased between the beginning (T1) and middle (T2) of patients' treatment and then increased again between the middle (T2) and end (T3) of patients' treatment. Using the Friedman's ANOVA test on patients who completed and returned data at all three time points (n=24), however, these changes were not statistically significant ($\chi^2=2.831$, $p=0.24$).

In summarising the analysis of patients' perceptions of control during the study, there were no statistically significant changes identified in patients' perceptions of personal control and their emotional representations during their six month course of chemotherapy treatment. There was a statistically significant reduction in patients' perceptions of treatment control between the beginning and end of patients' treatment, however, this finding was opposite to the initial hypothesis that perceptions of control would increase incrementally across each of the three time points. The findings from the analysis of the control related subscales, therefore, do not support the hypothesis that perceptions of control would increase incrementally between the beginning and end of patients' six month course of chemotherapy treatment and should be interpreted with caution owing to the relatively small sample size.

10.4 Patients' Perceptions of Self Efficacy

Two subscales of the SUPPH (shown in Appendix 3) were included in the analysis of patients' perceptions of their self efficacy at all three time points. These were 'positive attitudes' and 'stress reduction.' It was initially intended that the 'making decisions' subscale of the SUPPH would also be included in the analysis, however, as noted in Chapter 8, this subscale was excluded since it demonstrated poor internal reliability at all three data collection time points. Table 10.12 demonstrates the items that comprised both subscales of the SUPPH that were included in the analysis.

| Subscale | Items | Number of items |
|--------------------|--|-----------------|
| Positive Attitudes | 14, 15, 16, 18, 19, 20, 21, 22, 23, 24, 26, 27, 28, 29 | 14 |
| Stress Reduction | 1, 2, 3, 4, 5, 6, 8 | 7 |

Table 10.12: Selected subscales of SUPPH for analysis, items and number of items within each subscale

In accordance with the scoring instructions provided by Lev and Owen (1996), scores for all of the items on each subscale were summed to derive a value for the individual subscales at each time point (1=very little confidence to 5=very confident). Possible scores for each subscale ranged from 14-70 for the positive attitudes subscale and 7-35 for the stress reduction subscale. Higher scores on each subscale represents more positive perceptions of self efficacy. The data in Table 10.13 describes the median and range of values reported by the sample for both subscales at each data collection time point. Values have been rounded to one decimal place.

| Subscale | Time point | Median | Range |
|--------------------|---------------------|------------------|-----------|
| Positive Attitudes | Cycle 1 (T1) (n=24) | 52.5 (29.0/70.0) | 29.0-70.0 |
| | Cycle 3 (T2) (n=24) | 48.5 (24.0/70.0) | 24.0-70.0 |
| | Cycle 6 (T3) (n=24) | 49.5 (36.0/67.0) | 36.0-67.0 |
| Stress Reduction | Cycle 1 (T1) (n=24) | 21.0 (15.0/35.0) | 15.0-35.0 |
| | Cycle 3 (T2) (n=24) | 23.0 (11.0/34.0) | 11.0-34.0 |
| | Cycle 6 (T3) (n=24) | 22.5 (13.0/33.0) | 13.0-33.0 |

Table 10.13: Median and range of values reported by the sample for each subscale at T1, T2 and T3

The median values shown in Table 10.13 suggest a decrease in scores on the positive attitudes subscale between the beginning and end of treatment (appearing to peak slightly between the middle and end of patients' treatment). These findings suggest that there was a decrease in patients' perceptions of their self efficacy to maintain a positive attitude between the beginning (T1) and end (T3) of patients' treatment. Using the Friedman's ANOVA test on patients who completed and returned data at all three time points (n=24), however, this reduction was not statistically significant ($\chi^2=0.096$, $p=0.95$).

The median scores on the stress reduction subscale revealed that patients' perceptions of their self efficacy to reduce stress increased between the beginning (T1) and end (T3) of their treatment, appearing to peak in the middle (T2) of patients' treatment. Using the Friedman's ANOVA test on patients who completed and returned data at all three time points (n=24), this increase was identified as just being statistically significant ($\chi^2=6.167$, $p=0.05$). Post-hoc statistical analyses using the Wilcoxon Signed Rank Test identified that the increase in patients' perceptions of self efficacy to reduce stress nearly reached statistical significance ($p<0.05$) between the beginning (T1) and middle (T2) of patients' treatment ($z=1.796$, N-Ties=21, $p=0.07$), reflecting the peak as seen in the median scores at T2, with no further differences identified in any of the other post hoc comparisons.

In summary, there were no statistically significant changes identified in patients' perceptions of their self efficacy to maintain a positive attitude during their six month course of chemotherapy treatment. However, patients' perceptions of their self efficacy to reduce stress during their six month course of chemotherapy treatment appeared to peak in the middle of their treatment, almost reaching the level of statistical significance. Hence, although there is a trend towards a statistically significant increase in patients' perceptions of self efficacy to reduce stress, they do not support the hypothesis that perceptions of self efficacy would increase incrementally from the beginning to end of patients' treatment. The following section considers the association between the degree of self care carried out by patients and their perceptions of control and self efficacy at all three time points during patients' treatment.

10.5 Association Between Control, Self Efficacy and Self Care

Since the nature of the data from the subscales included in the analysis was ordinal, rather than interval, non parametric tests of correlation (Spearman's Rho) were used to test for statistically significant associations between patients' perceptions of control and the degree of self care that they had carried out during their treatment and between patients'

perceptions of their self efficacy and the degree of self care that they had carried out during their treatment. Furthermore, the researcher considered that since the data revealed that patients' median scores for control, self efficacy and degree of involvement in self care were clustered towards the upper end of the possible range of scores obtained for each variable (representing higher perceptions of control and self efficacy and a higher degree of self care being carried out amongst the sample), it was appropriate not to make assumptions about the normal distribution of the data and hence, non parametric tests were considered to be suitable. The data in Table 10.14 demonstrates the results of the analysis on the association between the control-related subscales (personal control, treatment control, and emotional representations) and the degree of self care carried out by patients over the course of their treatment.

| | | r_s | p (2-tailed) |
|-------------------------------------|----|--------|----------------|
| Personal control*Self care | T1 | 0.259 | 0.222 |
| | T2 | 0.177 | 0.407 |
| | T3 | 0.275 | 0.194 |
| Treatment control*Self care | T1 | 0.439 | 0.032* |
| | T2 | 0.313 | 0.136 |
| | T3 | 0.466 | 0.022* |
| Emotional representations*Self care | T1 | -0.186 | 0.383 |
| | T2 | 0.032 | 0.883 |
| | T3 | -0.325 | 0.122 |

* significant at $p < 0.05$

Table 10.14: Associations between control-related subscales and involvement in self care (n=24)

The values indicate that there were no statistically significant associations between 'personal control', and 'emotional representations' and the 'degree of self care carried out' by patients at all three time points (at $p < 0.05$). However, there was a statistically significant association between perceptions of 'treatment control' and the 'degree of self care carried out' by patients at the beginning (T1) ($p = 0.032$) and end (T3) ($p = 0.022$) of their treatment, but this did not achieve statistical significance in the middle of patients' treatment (T2). It is possible that had the sample size in the study been larger statistically significant associations may have been observed at all three time points for treatment control. The quantitative findings from the correlational analysis, therefore, tend to support

the hypothesis that patients' perceptions of treatment control were associated with carrying out a greater degree of self care during their six month course of treatment. These findings are further considered in relation to the qualitative data in Chapter 11.

The data in Table 10.15 demonstrates the results of the analysis on the association between the self efficacy-related subscales (positive attitude and stress reduction) and the degree of self care carried out by patients over the course of their treatment.

| | | <i>r_s</i> | <i>p</i> (2-tailed) |
|-----------------------------|----|----------------------|---------------------|
| Positive attitude*Self care | T1 | -0.019 | 0.931 |
| | T2 | -0.400 | 0.053 |
| | T3 | 0.366 | 0.078 |
| Stress reduction*Self care | T1 | 0.190 | 0.374 |
| | T2 | -0.104 | 0.629 |
| | T3 | 0.396 | 0.055 |

* significant at $p < 0.05$

Table 10.15: Association between self-efficacy related subscales and involvement in self care (n=24)

The values in Table 10.15 demonstrate that there were no statistically significant associations between patients' perceptions of their self efficacy to maintain a positive attitude and to reduce stress with the degree of self care that they carried out during their six month course of treatment. The hypothesis which proposed that as patients' perceptions of self efficacy increased, the degree of self care that they carried out would also increased was not supported in light of these findings.

Finally, since Chapter 4 highlighted that the constructs of perceived control and self efficacy are often believed to theoretically overlap and share similarities, the final section of the quantitative analysis set out to test the association between patients' perceptions of control and self efficacy in the current study. These findings are reported in section 10.6.

10.6 Association Between Perceived Control and Self efficacy

The data in Table 10.16 demonstrates the association between patients' perceptions of control and self efficacy at all three data collection time points. Like in the previous analysis, Spearman's Rho (r_s) tests of correlation were used owing to the ordinal nature of these variables and the trend towards scores being reported in the upper ranges of the possible range of scores for each variable.

| | | Positive attitude (SUPPH) | Stress reduction (SUPPH) |
|---|----|------------------------------|-----------------------------|
| Personal control (IPQ-R) | T1 | 0.305 | 0.139 |
| | T2 | 0.114 | 0.188 |
| | T3 | 0.277 | 0.282 |
| Treatment control (IPQ-R) | T1 | 0.562 * | 0.445* |
| | T2 | 0.279 | 0.336 |
| | T3 | 0.341 | 0.238 |
| Emotional representations (IPQ-R) | T1 | -0.475* | -0.528* |
| | T2 | -0.239 | -0.293 |
| | T3 | -0.445* | -0.391 |

* significant at $p < 0.05$

Table 10.16: Association between control and self efficacy-related subscales

The data in Table 10.16 shows that there was no statistically significant associations between the personal control subscale and the self efficacy related subscales, namely, positive attitude and stress reduction at all three time points during the study, suggesting that these subscales were not significantly correlated. The treatment control subscale, however, was statistically significantly correlated with both the self efficacy-related subscales i.e. positive attitude and stress reduction, at the beginning of patients' treatment (T1) but not at the middle (T2) or end (T3) of patients' treatment. The emotional representations subscale was statistically significantly correlated with one of the self efficacy-related subscales, namely the positive attitude subscale at the beginning (T1) and end (T3) but not in the middle (T2) of patients' treatment, whilst the emotional representations subscale was statistically significantly correlated with the other self efficacy-related subscale, namely, stress reduction at the beginning (T1) but not in the middle (T2) or end (T3) of patients' treatment. The findings from this analysis, therefore, demonstrate that the control and self efficacy-related subscales were correlated to a certain

degree at specific time points during the study suggesting that these constructs are related. However, the fact that the correlations, shown in Table 10.16, are modest and not consistent over time does not support the view that the constructs are in fact the same but with different labels.

10.7 Overall Summary of the Quantitative Analysis

The quantitative analysis of the self care diary identified that the majority of patients consistently carried out a high degree of self care throughout their six month course of treatment. There was a statistically significant increase in the degree of self care carried out between the beginning and middle of patients' treatment, however, this did not increase incrementally across the three time points as was initially hypothesised. The quantitative analysis of the self care diary also revealed that there was a slight but statistically significant increase in the use of fatigue-related self care strategies between the beginning and middle of patients' six month course of treatment. Again, however, this was not as was hypothesised and may have arisen due to chance because of the number of analyses being conducted. It was also noted that some self care activities were carried out more frequently than others for example, taking medications for nausea and diarrhoea seemed to be carried out to a lesser degree than other strategies. Contrasting findings were identified in the qualitative analysis which is further considered in Chapter 11 where the qualitative and quantitative data sets have been merged. A limitation of the quantitative analysis of the self care diary relates to the high degree of missing data found in several of its subscales (interference of side effects, confidence to perform self care, self care performed to prevent side effects or when side effects occurred, and the helpfulness of specific types of self care activities), meaning that analysis could not be performed on these scales. Furthermore, the trend towards the high degree of self care that patients reported they had carried out at each of the three time points limits the ability to demonstrate change over time. The researcher acknowledges these issues as limitations of the study and are further considered in Chapter 12.

The analysis of the quantitative questionnaires (IPQ-R and SUPPH) reveals that the patients in this study experienced fairly high perceptions of control and self efficacy throughout their six-month course of chemotherapy treatment. In relation to changes over time, there were no statistically significant changes identified in patients' perceptions of personal control and emotional representations across the three time points, but a statistically significant reduction in patients' perceptions of treatment control between the beginning and end of treatment. These findings, therefore, do not support the hypothesis that patients' perceptions of control increased incrementally over time between the beginning and end of patients' six month course of chemotherapy treatment. There were also no statistically significant changes identified in patients' perceptions of self efficacy to maintain a positive attitude but perceptions of their self efficacy to reduce stress increased between the beginning and middle of their treatment, almost reaching a statistically significant level. These findings, therefore, do not support the hypothesis that patients' perceptions of their self efficacy incrementally increased over time between the beginning and end of their six month course of chemotherapy treatment.

The quantitative analysis also set out to determine whether there were statistically significant associations between the control-related subscales and the degree of self care carried out by patients during their treatment, and the self efficacy-related subscales and the degree of self care carried out by patients during their treatment. The correlation analysis revealed that there was a statistically significant association between patients' perceptions of treatment control with the degree of self care that they carried out during their six month course of treatment. There were no other statistically significant associations between personal control, emotional representations, positive attitudes, and stress reduction and the degree of self care carried out by patients during their treatment. Hence, the quantitative findings from the correlation analysis support the hypothesis that patients' perceptions of treatment control were associated with carrying out a greater degree of self care during their

six month course of treatment, but not their perceptions of personal control or perceptions of self efficacy.

The findings reported here, however, should be treated with caution because of the small sample size and the possible lack of sensitivity of the instruments to detect changes in perceived control and self efficacy. Furthermore, the trend towards the high degree of self care and high perceptions of control and self efficacy that patients reported at each of the three time points limited the ability to demonstrate changes in these variables over time. These are acknowledged as limitations of the study and are further considered in Chapter 12.

The mixed method approach adopted in the study, however, was helpful in aiding further interpretation of the quantitative analysis, in order to provide a greater understanding of patients' self care behaviour, and the role of their perceptions of control and self efficacy. The findings from the merged analysis of both the qualitative and quantitative data sets are considered in the following chapter (Chapter 11).

Chapter 11 Merged Analysis

11.1 Introduction

The following chapter presents the merged findings from the analysis of the qualitative semi structured interviews and the analysis of the quantitative questionnaires and self care diaries which were reported separately in the previous chapters (Chapters 9 and 10). There were several key issues that emerged from the analyses presented in these chapters which will be considered further in the following chapter in which both the qualitative and quantitative data sets are merged.

Firstly, the *quantitative* analysis of the self care diary revealed that there was a significant increase in the degree of self care carried out between the beginning and middle of patients' six month course of chemotherapy treatment. There were, however, few changes in the types of self care activities that patients carried out with the exception of fatigue-related self care strategies, in which there was a statistically significant increase in their use between the beginning and middle of patients' treatment. The *qualitative* analysis revealed that fatigue was a significant side effect for patients and spoke of their self care strategies used to help manage this side effect. The *qualitative* analysis, however, also revealed that patients carried out a range of physical self care strategies, the use of which appeared to change between the beginning and end of their treatment, and also revealed the range of emotional self care strategies that were carried out by patients and how these changed between the beginning and end of patients' treatment.

Secondly, the *quantitative* analysis of the control-related subscales in the IPQ-R revealed that there were no statistically significant changes in patients' perceptions of personal control, however, there was a statistically significant reduction in patients' perceptions of treatment control between the beginning and end of their six month course of treatment. The *quantitative* analysis also demonstrated that patients consistently reported high perceptions of control at the beginning, middle and end of their treatment. The *qualitative*

analysis revealed that some patients perceived themselves to have a high degree of control over managing the effects of their treatment whilst others perceived themselves to have a low degree of control over managing the effects of their treatment.

Finally, the *quantitative* analysis of the control-related subscales of the IPQ-R revealed that there was no statistically significant associations between patients' perceptions of personal control and the degree of self care that they carried out during their treatment. The *qualitative* analysis, however, revealed that patients' perceptions of personal control were linked to their attitudes towards self care and their perceptions of its importance. The *quantitative* analysis also demonstrated a statistically significant positive association between patients' perceptions of treatment control and the degree of self care that they carried out during their treatment. In reflecting this, the *qualitative* analysis of the semi structured interviews, revealed that a key self care strategy used by patients at the beginning but also particularly at the end of their treatment was rationalising and comparing, in which they spoke of their beliefs in the efficacy of, and the necessity for, their chemotherapy treatment.

Thus, these findings suggest that the analysis of both the qualitative and quantitative data sets have revealed valuable and complementary findings in relation to patients' experiences of their involvement in self care and their perceptions of control. Thus, the findings from both data sets suggest that combining the qualitative and quantitative data could help to expand upon the understanding provided by each set of findings, offering a more complete picture of the perceptions and experiences of being involved in self care and perceptions of control held by the participants in this study. The analysis of the merged data sets for those patients who participated in the two qualitative semi-structured interviews, and who also completed the quantitative data at all three time points (n=8), are presented in this chapter in order to demonstrate how the qualitative findings can usefully contextualise and expand upon the quantitative findings and contribute towards a rich and in depth understanding of

patients' perceptions and experiences of their involvement in self care and their perceptions of control. The chapter begins by discussing the rationale for merging the data sets, the way in which the data sets were merged, the structure of presentation of this chapter, and the sample of patients who were included in the merged analysis, before continuing with a closer consideration of the findings.

11.2 Rationale for Merging Data

The chapters of the background literature section in this thesis highlighted a number of gaps which led to the focus of, and the design employed, in the current research study. In particular, the background chapters identified that there is a greater need to understand patients' perceptions and experiences of their involvement in self care and how factors such as perceived control are associated with their involvement in self care. However, this level of understanding has not yet been achieved, largely owing to the use of quantitative, cross sectional designs and studies which fail to adopt an individualised patient focus and a longitudinal approach. Subsequently, the current study aimed to combine the features of qualitative and quantitative methodologies in a patient-focussed, longitudinal approach to highlight how a mixed method approach can contribute towards a greater understanding of patients' perceptions and experiences of control and involvement in self care.

11.3 Merging the Data Sets

The qualitative and quantitative data sets for those patients who completed both of the qualitative semi structured interviews at the beginning and end of treatment and the quantitative data at all three time points at the beginning, middle and end of the study (n=8) were integrated for the purpose of the merged analysis. The process of integrating the qualitative and quantitative data sets was discussed in Chapter 6. To briefly reiterate, in accordance with the guidance set out by Tashakkori and Teddlie (1998) and Onwuegbuzie and Teddlie (2003), the qualitative (analysis of the semi-structured interviews) and quantitative (analysis of the control-related subscales in the IPQ-R and the self care diaries)

data sets were firstly analysed separately. Next, the quantitative data was ‘qualitised’ into categories of high, medium and low, based on the possible ranges of scores for each of the associated subscales. This is where the quantitative data are transformed into qualitative data in accordance with the guidance provided by Tashakorri and Teddlie (1998). This was important in order to facilitate an accurate comparison between the qualitative and quantitative data sets. These categories are shown in Table 11.1.

| Variable | Subscale | Range | Low | Medium | High |
|-----------------------------|--|-------|------|--------|-------|
| Control (IPQ-R) | Personal control | 6-30 | 6-13 | 14-20 | 21-30 |
| | Treatment control | 5-25 | 5-11 | 12-18 | 19-25 |
| Self Care (Self Care Diary) | Degree of self care carried out | 0-28 | 0-9 | 10-19 | 20-28 |
| | Types of specific self care activities carried out | 0-28 | 0-9 | 10-19 | 20-28 |

Table 11.1: Categories (low, medium and high) of scores for each subscale included in the merged analysis

Finally, the qualitative and ‘qualitised’ data sets were combined in tabular form to search for common themes and connections across the data sets (an example of one of these tables is shown in Appendix 10). The findings that were identified during this stage, for the patients who were included in the merged analysis, forms the basis of the following chapter.

11.4 Presentation of this Chapter

The following chapter discusses and depicts in tabular format, the degree of congruence and the connections between the qualitative and quantitative data sets for the patients who were included in the merged analysis and how combining the qualitative and quantitative data helps to expand upon the understanding provided by each set of findings in relation to patients’ experiences of self care and their perceptions of control. To facilitate an accurate comparison between the qualitative and quantitative data sets, the following chapter predominantly reports on patients’ *individual* scores that were reported at the beginning and end of treatment since the qualitative interviews were also conducted at the beginning and end of patients’ treatment only. The absence of an interview being conducted in the middle

of patients' treatment to correspond with the quantitative data collection is acknowledged as a limitation of the study design and is discussed in Chapter 12. Further statistical analysis on these eight patients for whom their data was merged is not conducted in this section because the small sample size would limit the meaningfulness of the analysis, however, median values and the range of values have been reported where indicated to convey evidence of trends in the data across the three time points.

It is also important to note that the qualitative excerpts presented in the following tables originated from the analysis of both the first and second sets of interviews, conducted at the beginning and end of patients' treatment respectively. Unless otherwise indicated, the set of interviews in which each quote originated is indicated in the following tables by 'interview 1', meaning that the quote originated from the first set of interviews, conducted at the beginning of treatment, and 'interview 2', meaning that the quote originated from second set of interviews, conducted at the end of patients' treatment.

Finally, of note, patients' perceptions of self efficacy are not considered in this chapter since the qualitative analysis presented in Chapter 9 noted that there was a lack of qualitative data on perceptions of self efficacy. Subsequently, it was not possible to compare this with the quantitative analysis of the self efficacy-related subscales. This is acknowledged as a limitation of the study and is considered further in Chapter 12. Furthermore, the following chapter focuses on the personal and treatment control subscales of the IPQ-R, rather than the emotional representations subscale since it was considered that this subscale, when integrated with the qualitative data, would not provide as specific information on perceptions of control as would the latter two subscales. Hence, the emotional representations subscale was not included in the merged analysis.

11.5 Demography of the Sample

The demography of the sample of patients who were included in the merged analysis is shown in Table 11.2 .

| Case | Age (yrs) | Gender | Social Class | Stage of Disease (Dukes') | Performance Status | Level of co-morbidity | Social Circumstances |
|------|-----------|--------|--------------|---------------------------|--------------------|-----------------------|---------------------------|
| 1 | 59 | Male | 4 | C | 1 | 1-2 | Lives with spouse/partner |
| 2 | 69 | Female | 6 | C | 0 | 1-2 | Lives with spouse/partner |
| 11 | 59 | Male | 7 | C | 0 | 0 | Lives with spouse/partner |
| 12 | 69 | Male | 7 | C | 0 | 1-2 | Lives with spouse/partner |
| 17 | 69 | Male | 5 | C | 0 | 0 | Lives with spouse/partner |
| 19 | 74 | Male | 2 | C | 0 | 1-2 | Lives with spouse/partner |
| 22 | 55 | Female | 3 | C | 0 | 1-2 | Lives alone |
| 24 | 49 | Female | 5 | B | 0 | 0 | Lives with spouse/partner |

Table 11.2: Demographic characteristics of patients who were included in the merged analysis

The sample of patients who were included in the merged analysis comprised both men and women, ranging in age from 49-74 years (mean age 62 yrs) and included patients living in a range of social classes from 2-7. One patient was diagnosed with Dukes' B stage colorectal cancer whilst the remainder had been diagnosed with Dukes' C. The majority of patients had a performance status of zero. In relation to patients' social circumstances, the majority of patients in the sub sample lived with their spouse and family.

11.6 Involvement in Self Care

Both the analysis of the qualitative semi structured interviews and the analysis of the quantitative self care diary with the full sample, as described in Chapters 9 and 10, were useful for providing information on how patients' involvement in self care changed during their treatment. Comparison of the findings reported in both of these chapters revealed some notable differences between the data sets relating to patients' experiences of being involved in self care at the beginning and end of their treatment. In particular, whilst the

quantitative analysis of the self care diary for the full sample (n=24) (reported in Chapter 10) revealed that there were few statistically significant changes in the types of specific self care strategies carried out by patients between the beginning, middle and end of patients' treatment, the qualitative analysis of the semi structured interviews (reported in Chapter 9) identified that there were changes in the types of self care activities that patients carried out at the beginning and end of their treatment.

The following discussion considers these findings in relation to the patients who were included in the merged analysis (n=8), beginning with a consideration of the degree of self care carried out by patients (section 11.6.1) and following with a discussion of the types of self care activities carried out by patients (section 11.6.2), and changes seen in the use of self care activities over time (section 11.6.3).

11.6.1 Degree of Self Care Carried Out

The quantitative analysis of the self care diary for the full sample who completed the diary at all three time points (n=24), presented in Chapter 10, found that there was a statistically significant increase in the degree of self care carried out by patients between the beginning (T1) and the middle (T2) of their treatment. The individual scores shown in Table 11.3 for each of the patients in the merged analysis reflects the fact that there was little change between the beginning and end of treatment.

| Case | Beginning of Treatment (cycle 1/T1) | End of Treatment (cycle 6/T3) |
|---------------------|--|----------------------------------|
| Study Median | High (27.5) | High (28.0) |
| 1 | Low (8.0) | Low (8.0) |
| 2 | High (28.0) | High (28.0) |
| 11 | High (27.0) | High (27.0) |
| 12 | High (28.0) | High (28.0) |
| 17 | High (28.0) | High (28.0) |
| 19 | Med (18.0) | Med (18.0) |
| 22 | Med (12.0) | Med (12.0) |
| 24 | Low (7.0) | Low (7.0) |

Table 11.3: Individual values for degree of self care carried out at the beginning and end of treatment as reported by patients (n=8) in the merged analysis

The qualitative data from the semi structured interviews of the eight patients who were included in the merged analysis supported the quantitative findings from the self care diaries of these patients in terms of the high degree of self care that was carried out by the majority of patients at both the beginning and end of their treatment. There were four patients, however, who reported in the self care diary that they had carried out a lesser degree of self care and hence, were categorised as carrying out a lower degree of self care at the beginning and end of their treatment (patients 1, 19, 22 and 24). In merging the data sets, however, the qualitative analysis revealed additional information. In particular, the following examples from the qualitative analysis, demonstrated in Table 11.4, highlight that these patients did report carrying out a high degree of self care like the other patients in the merged analysis.

| Case | Quantitative Score at beginning/end of treatment (degree of self care carried out) | Excerpts from the qualitative data at beginning/end of treatment |
|------|--|---|
| 1 | Low/Low | <p>"I'm finding no real problems...with the treatment you've just got to wait and see really." (Interview 1)</p> <p>Medication's there is you need it but I'm not going to jump the gun. I'm a great believer in the more it gets used...your body gets used to it." (Interview 1)</p> <p>"I'm not a pill taker anyway and I'm one of these folk that can be quite dogmatic about something like this." (Interview 2)</p> <p>"I've been lucky in that I've been fairly constant all the way through. I know that some of the symptoms could change as you go through but I've not been like that, I've been fairly steady all the way through and really it's just been tiredness and feeling a bit sick. Apart from that it's not really bothered me much...I've been lucky I suppose." (Interview 2)</p> |
| 24 | Low/Low | <p>"It's [the side effects] a small price to pay and I'll manage fine. It's only a temporary thing that'll happen to me, I'll be fine about it." (Interview 1)</p> <p>"Right now I feel I'm the person I always was and I've been lucky that this has been caught and I'm having the treatment, and I'll be back before they know it." (Interview 1)</p> <p>"The side effects have all been minimal, they've been mildly irritating for some of them but they've been bearable, I've managed to cope with them all." (Interview 2)</p> <p>I was given anti-nausea and immodium for diarrhoea...but it [the diarrhoea] wasn't bad enough to take anything for it. I don't think my side effects were significant enough to take anything preventatively." (Interview 2)</p> |
| 19 | Medium/Medium | <p>"I believe that people can get some terrible side effects...sickness, vomiting...I've not had anything like that." (Interview 1)</p> <p>"I feel I'm being well looked after and I'm not on my own if you know what I mean, I've always got somebody to go to." (Interview 1)</p> <p>"It wasn't any bother at all...it wasn't as bad as I thought it was going to be." (Interview 2)</p> <p>"You knew what was causing it [the side effects] and you knew it was going to go away...you're able to thole it when you knew it was going to go away." (Interview 2)</p> |
| 22 | Medium/Medium | <p>"The side effects are something I've got to endure." (Interview 1)</p> <p>"Anti-sickness tablets don't really help with the nausea. They stop you being sick but it's a kind of sickness feeling so it never really goes away." (Interview 1)</p> <p>I don't know if it [self care] helps. It might make me feel a little bit more comfortable but I don't know if it actually alleviates the side effects or if they just run their course." (Interview 1)</p> <p>"I started to dread each month because despite the fact I knew I could get these things [medication] I knew I would have the symptoms anyway so I knew that they would alleviate it a little but they wouldn't stop it," (Interview 2)</p> <p>"Nothing that they were going to give me could prevent it or make me feel totally comfortable." (Interview 2)</p> |

Table 11.4: Perceptions of a lower degree of physical self care carried out in the self care diary and semi structured interviews as reported by patients in the merged analysis

The examples in Table 11.4 also demonstrate that these patients may have reported a lesser degree of self care in the self care diary since they may have perceived a lesser need for physical self care, which the diary had only been designed to measure. Therefore, the diary did not identify the degree of emotional self care that was carried out by patients. The structure of the diary in limiting patients' responses towards self care has been acknowledged as a limitation of the study in Chapter 12. Furthermore, the qualitative analysis identified that patients may not have expected to play a role in their physical self care, preferring to rely on health professionals (this was a key self care strategy that was used by all patients in the study as revealed in the qualitative analysis of the semi structured interviews (Chapter 9)). These patients also spoke of a preference not to use medication, despite it being perceived as a key self care strategy in the qualitative analysis, and rationalised that their treatment was necessary (Table 11.4). Consequently, they perceived themselves to be lucky and that the side effects were a small price to pay (Table 11.4). Furthermore, one patient (patient 24) revealed in the qualitative interviews that she doubted the efficacy of her self care, which may have influenced the extent to which she reported carrying out physical self care strategies in the quantitative self care diary (Table 11.4).

11.6.2 Types of Self Care Activities

The findings from the qualitative analysis of the semi structured interviews and the quantitative analysis of the self care diaries, as reported in Chapters 9 and 10, were also useful for identifying the types of self care activities that patients carried out during their treatment and whether their patterns of use varied between the beginning and end of their treatment. In particular, the qualitative analysis of the interviews was valuable since it was possible to distinguish between the self care activities that patients carried out in managing both the physical and emotional impacts of treatment. This was important because the quantitative self care diary focussed only on self care activities employed to manage the physical impact of their treatment and hence, it was only able to focus on patients' physical self care. The qualitative analysis of the interviews, reported in Chapter 9, also highlighted

that patients reported a greater range of emotional self care strategies than they did in relation to managing the physical impact of their treatment and was particularly useful for identifying other types of self care activities that patients carried out in helping them to manage the physical impact of their treatment, such as relying on health professionals, which were not focussed upon in the self care diary.

Table 11.5 provides a reminder of the specific self care activities that were included in the quantitative self care diary, and their associated codes which have been used to denote these activities in Tables 11.6-11.9. The data in Tables 11.6-11.9 highlight the frequency with which each specific self care activity was carried out by the sub sample of patients in the merged analysis at the beginning and end of their treatment.

| Physical Side Effect | Code | Self Care Activities |
|----------------------|------|---|
| Diarrhoea | D1 | Watch for any changes with your bowels |
| | D2 | Take anti-diarrhoea tablets |
| | D3 | Maintain personal hygiene |
| | D4 | Watch or change your diet (e.g. increased intake of high fibre foods) |
| | D5 | Drink plenty fluids |
| Nausea/Vomiting | NV1 | Take anti-sickness tablets |
| | NV2 | Watch or change your diet (e.g. eat small and frequent meals) |
| | NV3 | Relaxation and distraction exercises |
| Mucositis | M1 | Watch for any changes with your mouth |
| | M2 | Use regular mouthwashes |
| | M3 | Clean teeth regularly |
| | M4 | Use a throat spray or lozenges |
| | M5 | Drink plenty fluids |
| | M6 | Watch or change your diet (e.g. avoid hard or crunchy foods) |
| Fatigue | F1 | Stop and rest when needed |
| | F2 | Gently exercise when you can |
| | F3 | Eat a healthy, balanced diet |

Table 11.5: List of specific self care activities for each side effect

| Case | D1 (start/end) | D2 (start/end) | D3 (start/end) | D4 (start/end) | D5 (start/end) |
|---------------------|------------------------------------|---------------------------------|-------------------------------------|---------------------------------|-------------------------------------|
| Study Median | Med (14.0)/ High (20.0) | Low (1.0)/ Low (1.0) | High (20.5)/ High (26.0) | Low (4.0)/ Low (9.0) | High (20.0)/ High (26.0) |
| 1 | Low (6.0)/ Med (11.0) | Low (0.0)/ Low (0.0) | Low (6.0)/ Med (11.0) | Low (0.0)/ Low (0.0) | Low (6.0)/ Med (10.0) |
| 2 | Low (1.0)/ Low (0.0) | Low (0.0)/ Low (0.0) | Low (1.0)/ Low (0.0) | Low (1.0)/ Low (0.0) | Low (1.0)/ Low (0.0) |
| 11 | High (26.0)/ High (27.0) | Low (8.0)/ Low (1.0) | High (28.0)/ High (28.0) | High (21.0)/ High (21.0) | High (27.0)/ High (28.0) |
| 12 | Med (11.0)/ Med (11.0) | Low (4.0)/ Low (1.0) | High (26.0)/ High (26.0) | Low (1.0)/ Med (12.0) | High (28.0)/ High (25.0) |
| 17 | Low (0.0)/ Low (0.0) | Low (1.0)/ Low (8.0) | High (27.0)/ High (27.0) | Low (1.0)/ Low (0.0) | Low (1.0)/ High (28.0) |
| 19 | Low (1.0)/ Med (16.0) | Low (0.0)/ Med (10.0) | Low (2.0)/ High (28.0) | Low (0.0)/ Low (0.0) | Low (1.0)/ High (28.0) |
| 22 | Med (12.0)/ Low (5.0) | Low (0.0)/ Low (0.0) | Med (12.0)/ Low (6.0) | Low (2.0)/ Low (0.0) | Med (11.0)/ Low (4.0) |
| 24 | Low (0.0)/ Low (4.0) | Low (0.0)/ Low (0.0) | Low (0.0)/ Low (4.0) | Low (0.0)/ Low (4.0) | Low (0.0)/ Low (4.0) |

Table 11.6: Individual scores for diarrhoea-related self care activities carried out at the beginning and end of treatment as reported by patients in the merged analysis (n=8)

| Case | NV1 (start/end) | NV2 (start/end) | NV3 (start/end) |
|---------------------|----------------------------|----------------------------|----------------------------|
| Study Median | Low (1.5)/Low (1.5) | Low (3.0)/Low (4.5) | Med (5.0)/Low (4.5) |
| 1 | Low (0.0)/Low (5.0) | Low (0.0)/Low (0.0) | Low (0.0)/Low (0.0) |
| 2 | Low (0.0)/Low (0.0) | Low (0.0)/Low (0.0) | Low (0.0)/Low (0.0) |
| 11 | Low (1.0)/Low (4.0) | High (21.0)/High (21.0) | High (28.0)/High (28.0) |
| 12 | Low (5.0)/Low (0.0) | Low (2.0)/Low (8.0) | Low (1.0)/Low (1.0) |
| 17 | Low (0.0)/Low (0.0) | Low (0.0)/Low (0.0) | Low (0.0)/Low (0.0) |
| 19 | Low (0.0)/Low (7.0) | Low (0.0)/Low (0.0) | Low (0.0)/Low (0.0) |
| 22 | Low (3.0)/Low (8.0) | Low (0.0)/Low (0.0) | Low (1.0)/Low (0.0) |
| 24 | Low (0.0)/Low (0.0) | Low (0.0)/Low (2.0) | Low (0.0)/Low (0.0) |

Table 11.7: Individual scores for nausea and vomiting-related self care activities carried out at the beginning and end of treatment as reported by patients in the merged analysis (n=8)

| Case | M1 (start/end) | M2 (start/end) | M3 (start/end) | M4 (start/end) | M5 (start/end) | M6 (start/end) |
|---------------------|-----------------------------------|----------------------------------|-------------------------------------|---------------------------------|-------------------------------------|---------------------------------|
| Study Median | Med (14.5)/ Med (13.5) | Low (8.5)/ Med (11.0) | High (25.5)/ High (26.5) | Low (1.5)/ Low (1.0) | High (24.5)/ High (27.0) | Low (7.0)/ Low (7.0) |
| 1 | Low (3.0)/ Low (0.0) | Low (0.0)/ Low (0.0) | Low (5.0)/ Low (0.0) | Low (0.0)/ Low (0.0) | Low (5.0)/ Low (0.0) | Low (0.0)/ Low (0.0) |
| 2 | High (24.0)/ Med (13.0) | High (24.0)/ Low (3.0) | Med (17.0)/ Low (3.0) | Low (6.0)/ Low (1.0) | High (24.0)/ Low (3.0) | High (24.0)/ Low (8.0) |
| 11 | High (26.0)/ Med (17.0) | Low (2.0)/ Low (1.0) | High (26.0)/ High (28.0) | Low (2.0)/ Low (0.0) | High (28.0)/ High (28.0) | High (22.0)/ High (21.0) |
| 12 | Med (13.0)/ Low (3.0) | High (25.0)/ Low (3.0) | High (26.0)/ High (27.0) | Low (2.0)/ Low (1.0) | High (25.0)/ High (27.0) | Low (2.0)/ High (21.0) |
| 17 | Low (1.0)/ Low (3.0) | High (26.0)/ High (27.0) | High (27.0)/ High (27.0) | Low (2.0)/ Low (2.0) | High (25.0)/ High (26.0) | Low (2.0)/ Low (2.0) |
| 19 | Low (9.0)/ Med (14.0) | Low (6.0)/ Med (12.0) | Med (11.0)/ High (25.0) | Med (11.0)/ Low (6.0) | Low (9.0)/ High (27.0) | Low (5.0)/ Low (0.0) |
| 22 | Med (12.0)/ Low (9.0) | Med (12.0)/ Low (9.0) | Med (11.0)/ Low (9.0) | Low (5.0)/ Low (5.0) | Med (11.0)/ Low (4.0) | Low (3.0)/ Low (0.0) |
| 24 | Low (7.0)/ Low (5.0) | Low (7.0)/ Low (5.0) | Low (7.0)/ Low (5.0) | Low (2.0)/ Low (0.0) | Low (7.0)/ Low (5.0) | Low (7.0)/ Low (5.0) |

Table 11.8: Individual scores for mucositis-related self care activities carried out at the beginning and end of treatment as reported by patients in the merged analysis (n=8)

| Case | F1 (start/end) | F2 (start/end) | F3 (start/end) |
|---------------------|--------------------------------|-------------------------------|-------------------------------|
| Study Median | High (24.5)/High (24.5) | High (20.5)/High(25.0) | High (23.5)/High(22.5) |
| 1 | Low (8.0)/Med (12.0) | Low (7.0)/Med (12.0) | Low (0.0)/Med (12.0) |
| 2 | High (26.0)/High (24.0) | Low (0.0)/High (24.0) | High (26.0)/High (24.0) |
| 11 | High (28.0)/High (27.0) | High (28.0)/High (27.0) | High (27.0)/High (27.0) |
| 12 | High (26.0)/High (27.0) | High (28.0)/High (26.0) | Low (2.0)/Low (4.0) |
| 17 | High (26.0)/High (27.0) | High (27.0)/High (28.0) | High (27.0)/High (28.0) |
| 19 | Low (0.0)/Med (19.0) | Low (0.0)/Low (1.0) | Low (0.0)/Low (1.0) |
| 22 | Low (3.0)/Low (9.0) | Low (8.0)/Low (4.0) | Low (7.0)/Low (5.0) |
| 24 | Low (0.0)/Low (2.0) | Low (0.0)/Low (2.0) | Low (0.0)/Low (2.0) |

Table 11.9: Individual scores for fatigue-related self care activities carried out at the beginning and end of treatment as reported by patients in the merged analysis (n=8)

As shown in the data in tables 11.6-11.9, the most common self care activities that were reported being carried out in the quantitative self care diary by the eight patients who were included in the merged analysis included; taking care with personal hygiene and drinking plenty fluids for managing diarrhoea, finding ways to relax and distract oneself for managing nausea and vomiting, cleaning teeth regularly and drinking plenty fluids to help managed mucositis, and the most common activities for managing fatigue included, stopping and resting. These activities were amongst the most frequent activities carried out at both the beginning and end of patients' treatment, and their use during patients' treatment was supported by their accounts within the qualitative data as described in Chapter 9.

In particular, the analysis of the quantitative self care diaries for the eight patients that were included in the merged analysis, like in the full analysis described in Chapter 10, identified that a high degree of each of the fatigue-related self care activities were reported. Indeed, this was supported by the qualitative data from their semi structured interviews which revealed that the experience of fatigue had the biggest physical impact on several patients, even amongst those who commented that they had experienced few physical side effects during their treatment. Some excerpts from the qualitative data from the interviews conducted at the end of patients treatment amongst the eight patients included in the merged analysis are shown in Table 11.10 to highlight this.

| Case | Excerpts from the qualitative data at end of patients' treatment |
|------|--|
| 2 | <p>"The last week of my treatment I was very very tired. More tired than I was any other, well more tired than I was [cycles] 2, 3, 4 and 5 cos the first month I was tired and this month I've been very tired. Like I went out with my friends on Wednesday as usual thinking I'd be okay and by the time I got home, I was straight to bed."</p> <p>"I didn't have the energy to do very much and I love going on holiday and I haven't been able to do that even to do to friends to get there it'd be too much you know."</p> <p>"It's not tiredness, it's fatigue. When you're tired you tend to carry on but this type of tiredness...you just can't carry on."</p> |
| 19 | <p>"It does take you down you know I'm a bit weak and I do walk but I have to stop to get my breath back if I'm going a distance."</p> <p>"I was falling asleep on the chair but I think I was just tired. The chemo was taking it out of me."</p> |
| 24 | <p>"Pulse five, week three was the worst I felt in as much as I felt there was some sort of leaden weight on my body. I was so fatigued, I couldn't do particularly much."</p> <p>"I'm always really on the go and everything and I've not really had the same energy levels that I had before this happened to me."</p> |

Table 11.10: Perceptions of fatigue identified in qualitative interviews conducted at the end of patients' treatment with patients in the merged analysis

It is particularly interesting to note that the analysis of the quantitative self care diary data for the full sample (n=24), reported in Chapter 10, identified that the activities that were performed the least by patients, both at the beginning and end of treatment, were those relating to the use of medications, for example, anti-emetics for helping to manage nausea and vomiting, anti-diarrhoea tablets to control diarrhoea, and mouthwashes to control mucositis. This is interesting since the qualitative analysis, reported in Chapter 9, highlighted patients' reliance on medication as one of their key self care strategies that they consistently used throughout the duration of their treatment. Similar findings were identified amongst the quantitative and qualitative data sets for the sub sample of patients included in the merged analysis. The qualitative excerpts in Table 11.11 from the sub sample of patients in the merged analysis demonstrates their use of, and in many cases, reliance on medication at both the start and end of their treatment.

| Case | Excerpts from the qualitative data at the beginning and end of patients' treatment |
|------|---|
| 1 | "I've got anti-sickness pills, I've got anti-diarrhoea pills, mouthwashes for mouth ulcers which seems to be about the normal." (Interview 1) "If I'm feeling sick, I'll take the tablets and get on with it." (Interview 2) |
| 2 | "I suppose if I do feel sick, I'm just hoping that the anti-sickness tablets they've given me is going to work and if not, apparently I've got to go to the doctor...perhaps he'll prescribe something else." (Interview 1) "I knew because I had the mouthwashes...I knew I could control the mouth, that it wouldn't get to a stage that it did that first month." (Interview 2) |
| 11 | "I think you've only got two options...medication, and if that doesn't work then seek advice." (Interview 1) "It's just the fourth, fifth and sixth one that sort of brought me down a wee bit you know...a wee bit more "what will I do"...I've got these pills here I just take for diarrhoea, 'what will I do for nausea', I'll just take these oils and if I felt that these werenae working, I'd just phone [the nurse]." (Interview 2) |
| 12 | "I would take what's prescribed to me and that's what I do take...I take what's prescribed to me and follow their [doctor] guidelines." (Interview 1) "...sickness well they gave me lots of stuff to take. I had diarrhoea...they gave me stuff to take and it was very successful." (Interview 2) |
| 17 | "I've got treatment there if I've got any diarrhoea or anything...I can get remedies for anything that happens to me." (Interview 1) "They [the doctors] supply tablets for diarrhoea. I just took tablets for diarrhoea." (Interview 2) |
| 19 | "I've had absolutely no sickness...constipated...I've got stuff from the doctor for that as well. My mouth was really but obviously what you do is go to the doctor. He's given me tablets in case it comes back again." (Interview 1) "[I had]...sore mouth at times but I just got tablets...the hospital gave me tablets. I had senna for the constipation and loperamide and domperidone [for the sickness]. I didn't take anything to ward it off, I just waited till the came on and then took it and they more or less worked...everything they gave you worked." (Interview 2) |
| 22 | "I didn't feel great but I felt I knew I could get the anti-sickness tablets, mouthwashes and things like that." (Interview 2) |

Table 11.11: Perceptions of medication use identified in qualitative interviews conducted at the beginning and end of patients' treatment with patients in the merged analysis

Furthermore, the analysis of the quantitative self care diary amongst the sub sample of patients in the merged analysis also identified that patients carried out less strategies in relation to making dietary changes in helping to manage diarrhoea and nausea and vomiting for example, eating small regular meals. Their qualitative data, however, revealed that patients reported a high degree of involvement in such activities as part of their attempts to adapt to, and compensate for, the impact of their treatment at the beginning and particularly at the end of their treatment. In particular, patients in the merged analysis, and also the full analysis (Chapter 9), described the importance of monitoring their weight loss, learned what foods to avoid which might aggravate side effects or cause problems with their stoma, drinking using a straw, or taking a liquid diet when feeling nauseous or experiencing mucositis. Table 11.12 highlights some examples from the patients in the merged analysis.

| Case | Excerpts from the qualitative data at the beginning and end of patients' treatment |
|------|--|
| 1 | "I tend to be a wee bit more careful about what I'm eating and drinking now." (Interview 2) |
| 2 | "I had the sore mouth, it wasn't ulcers it was just you couldn't take anything hot so I used to drink liquids through a straw." (Interview 2) |
| 12 | "I just don't eat, I take fluids, drink lots of different kinds of fluids...I've tried to get into the habit of the second week I don't eat, that's why I was keeping a check of my weight every Sunday." (Interview 2) |
| 19 | "I was taking soups to begin with and I really couldn't tell you what they were but they went down I didn't have to chew them and they weren't in my mouth for that long." (Interview 2) |
| 22 | "My throat almost felt like it was closing up for about 5 days and I couldn't eat properly for a few days and I was on the fortisips [nutritional drinks]." (Interview 1) "Fruit and vegetables are difficult cos I'm still experimenting with those so healthy eating's something I'm working on right now." (Interview 1) |
| 24 | "There's certain things I just don't eat...you can tell what foods you're not digesting properly so I just cut them out as well." (Interview 2) |

Table 11.12: Examples of the use of adaptive strategies by patients in the merged analysis at the beginning and end of their treatment

On the other hand, in support of the quantitative diary data, two patients (patients 11 and 17) from the sub sample of patients in the merged analysis highlighted in the qualitative interviews at the end of their treatment that they had not altered their diet, as shown in the excerpts in Table 11.13. Their quotes suggest that this was because they had rationalised that the treatment had had little impact on them physically, meaning that they had had to make little lifestyle changes during their treatment, or that not altering their diet was an important part of their emotional self care in maintaining a sense of normality.

| Case | Excerpts from the qualitative data at the end of patients' treatment |
|------|---|
| 11 | "[I] have a curry at least once a week...because I don't want to break my routine. What we'll do is try to have a curry one night and then a pizza of things like that the other night and it's important." (Interview 2) |
| 17 | "I've not altered my diet or anything like that...just ate a normal diet...just the same." (Interview 2) |

Table 11.13: Patients' perceptions of not altering their diet from the qualitative data

11.6.3 Changes in Types of Self Care Activities

In relation to changes in the types of self care activities that were carried out by patients between the beginning and end of their treatment, the quantitative analysis of the self care diaries of the full sample (n=24), reported in Chapter 10, found few statistically significant differences in the use of specific types of self care activities during patients' treatment. Only the use of one fatigue related self care activity, namely, stopping and resting, seemed

to increase between the beginning and middle of patients' treatment (as reported in Chapter 10.) Statistical analysis of the use of specific self care activities for the sample of patients included in the merged analysis (n=8) has not been conducted here because the size of the sample limits the meaningfulness of this analysis. Table 11.14, however, reports the median scores and the range of scores (noted in brackets) for each self care activity used by these patients at the beginning and end of their treatment to convey trends in the data.

| | | Beginning of treatment (T1, cycle 1) | End of treatment (T3, cycle 6) |
|-------------------|-----|--------------------------------------|--------------------------------|
| Diarrhoea | D1 | Low - 3.5 (0.0-26.0) | Low - 8.0 (0.0-27.0) |
| | D2 | Low - 0.0 (0.0-8.0) | Low - 0.0 (0.0-10) |
| | D3 | Low - 9.0 (0.0-28.0) | Medium - 18.5 (0.0-28.0) |
| | D4 | Low - 1.0 (0.0-21.0) | Low - 0.0 (0.0-21.0) |
| | D5 | Low - 8.5 (0.0-28.0) | Medium - 17.5 (0.0-28.0) |
| Nausea & Vomiting | NV1 | Low - 0.0 (0.0-5.0) | Low - 2.0 (0.0-8.0) |
| | NV2 | Low - 0.0 (0.0-21.0) | Low - 0.0 (0.0-21.0) |
| | NV3 | Low - 0.0 (0.0-28.0) | Low - 0.0 (0.0-28.0) |
| Mucositis | M1 | Medium - 10.5 (1.0-26.0) | Low - 7.0 (0.0-17.0) |
| | M2 | Medium - 9.5 (0.0-26.0) | Low - 7.0 (0.0-27.0) |
| | M3 | Medium - 14.0 (5.0-27.0) | Medium - 19.0 (0.0-28.0) |
| | M4 | Low - 2.0 (0.0-11.0) | Low - 1.0 (0.0-6.0) |
| | M5 | Medium - 17.5 (5.0-28.0) | Medium - 19.5 (0.0-28.0) |
| | M6 | Low - 4.0 (0.0-24.0) | Low - 3.5 (0.0-21.0) |
| Fatigue | F1 | Medium - 17.0 (0.0-28.0) | High - 21.5 (2.0-27.0) |
| | F2 | Low - 7.5 (0.0-28.0) | Medium - 18.0 (1.0-28.0) |
| | F3 | Low - 4.5 (0.0-27.0) | Low - 8.5 (1.0-28.0) |

Table 11.14: Median and range of values for use of specific self care activities in patients included in the merged analysis (n=8)

The median values reported in Table 11.14, are useful for identifying that there appeared to be little evidence of a trend towards increased self care activity from the beginning to end of treatment. Hence, the quantitative data seems to support the view that patients did not greatly alter their use of specific self care activities during their treatment. The qualitative analysis, reported in Chapter 9, however, suggested that patients' use of self care strategies did change between the beginning and end of their treatment. In particular, they used a greater range of adaptive strategies such as, being careful about their diet, avoiding eating when feeling nauseous and avoiding foods that weren't digested easily, and ways to limit the impact of fatigue. Furthermore, the qualitative analysis identified that patients' use of emotional self care strategies changed over time with patients' use of rationalising and comparing becoming greater towards the end of their treatment. The self care diary,

however, was unable to identify patients' use of emotional self care strategies since this was designed to measure physical strategies only. The limitation of this is further discussed in Chapter 12.

11.7 Perceptions of Control

The analysis of the qualitative semi structured interviews and the analysis of the quantitative control-related subscales of the IPQ-R, reported in Chapters 9 and 10, were useful for providing information on patients' perceptions of control and how these changed during their treatment. In particular, the quantitative analysis of the personal control and treatment control subscales in the IPQ-R amongst the full sample (n=24) (reported in Chapter 10) revealed that there were no significant changes in patients' perceptions of control at the beginning, middle and end of their six month course of treatment. The quantitative analysis of the full sample (n=24) also demonstrated that patients consistently reported high perceptions of control at the beginning, middle and end of their treatment. Similar findings were reflected in the analysis of the control related subscales amongst the patients included in the merged analysis (n=8). The qualitative data, however, suggested that there were patients who perceived themselves to have a high degree of control but others who perceived themselves to have a low degree of control at both the beginning and end of their treatment. The following section considers these findings in further detail.

11.7.1 Degree of Control Perceived by Patients

The quantitative analysis of the personal and treatment control subscales of the IPQ-R for the full sample (n=24), presented in Chapter 10, revealed that the patients who participated in this study reported high perceptions of personal and treatment control at the beginning (T1) and end of their treatment (T3). Similar findings were reported in the quantitative analysis of the personal and treatment control subscales of the IPQ-R for patients included in the merged analysis (n=8), as shown in Tables 11.15 and 11.16.

| Case | Beginning of Treatment (cycle 1/T1) | End of Treatment (cycle 6/T3) |
|---------------------|--|----------------------------------|
| Study Median | High (22.0) | High (21.0) |
| 1 | High (22.0) | High (22.0) |
| 2 | High (22.0) | High (23.0) |
| 11 | High (23.0) | Med (19.0) |
| 12 | High (30.0) | High (22.0) |
| 17 | High (24.0) | High (22.0) |
| 19 | Med (19.0) | Med (19.0) |
| 22 | Med (19.0) | High (21.0) |
| 24 | High (24.0) | Med (16.0) |

Table 11.15: Individual scores for 'personal control' at the beginning and end of treatment as reported by patients (n=8) in the merged analysis

| Case | Beginning of Treatment (cycle 1/T1) | End of Treatment (cycle 6/T3) |
|---------------------|--|----------------------------------|
| Study Median | High (20.0) | High (19.5) |
| 1 | High (20.0) | Med (17.0) |
| 2 | High (24.0) | High (20.0) |
| 11 | High (19.0) | Med (18.0) |
| 12 | High (25.0) | High (20.0) |
| 17 | High (19.0) | High (20.0) |
| 19 | Med (16.0) | Med (17.0) |
| 22 | Med (18.0) | High (20.0) |
| 24 | High (20.0) | High (19.0) |

Table 11.16: Individual scores for 'treatment control' at the beginning and end of treatment as reported by patients (n=8) in the merged analysis

The integration of the qualitative and quantitative findings for the eight patients included in the merged analysis was useful for comparing patients' perceptions of control within both data sets and for explaining patients' perceptions of their personal and treatment control. In particular, the analysis of the merged data revealed that patients who reported medium and high perceptions of personal control in the quantitative analysis of the IPQ-R also identified positive perceptions in being able to manage the impact of their treatment within the qualitative semi structured interviews. As noted in Chapter 9 in relation to the full sample (n=11), the qualitative data for the patients in the merged analysis also revealed that perceptions of personal control were related to the degree to which people perceived they had influence over their side effect experiences, their desire to, and the importance of, being actively involved in their self care, their expectations of health professionals, their perceptions of the chemotherapy treatment and medications, and the impact of the treatment

on their physical and emotional well being. Some examples of these perceptions from the qualitative data are shown in Table 11.17.

| Case | Quantitative Score at start and end of treatment (personal control) | Excerpts from the qualitative data at beginning and end of treatment |
|------|---|---|
| 1 | High/High | <p>“The fitter you keep yourself, the better that helps you cope with illness. I was lucky I was fit and still reasonably fit and there’s very few things even yet...you know if I want to do something I’ll go and do it, that’s my nature” (Interview 1)</p> <p>“To be honest, it’s [the treatment] not really bothered me one way or another. I’ve done most things, been places, life’s not bad.” (Interview 2)</p> <p>“The same things [medications] have worked for me right through.” (Interview 2)</p> |
| 2 | High/High | <p>“I was very fortunate I didn’t have the sickness and diarrhoea” (Interview 2)</p> <p>“I knew because I had all the mouthwashes, I knew I could control the mouth that it wouldn’t get to a stage that it did the first month you know...I knew I could control it.” (Interview 2)</p> <p>“I came up there and asked the Sister about a wig. I was quite happy with it...I just feel so good...I feel very confident now that I’ve got a wig.” (Interview 2)</p> |
| 11 | High/Med | <p>“Everything seems to be okay...I’m not taking pills or anything like that and I feel I’m okay that way. I’m coping so far.” (Interview 1)</p> <p>“It’s been an even keel. The side effects I was told about before, the things that can happen have not materialised. Everything seems to be not too bad.” (Interview 2)</p> |
| 12 | High/High | <p>“Nothing’ll bother me [the side effects]. It’s not worth bothering about more than making sure you’re going to survive at the end of the day.” (Interview 1)</p> |
| 17 | High/High | <p>“The week immediately after your treatment is always the worst week, that’s when you get the majority of side effects and then it starts to taper off the next two weeks, then you’re back into the treatment again. They’re just uncomfortable.” (Interview 2)</p> <p>“I’ve just lived a normal life through this, it’s not affected me greatly one way or the other.” (Interview 2)</p> <p>“I never had any severe side effects. I know it affects different people in different ways but I was quite well as far as side effects is concerned.” (Interview 2)</p> |
| 22 | Med/High | <p>“I didn’t feel great but I knew I could get the antisickness tablets, mouthwashes, things like that.” (Interview 2)</p> |
| 24 | High/Med | <p>“I was very structured. I knew that week one was the chemo week, week two I felt pretty bad, week three was recovering and week four was back to my old self again.” (Interview 2)</p> <p>“The chemo itself was nothing like I expected...it was just so easy. You know I can’t honestly say it was dreadful, it was bearable, the side effects weren’t drastic.” (Interview 2)</p> <p>“I’ve had the same level of control I think...just because the side effects have been all round about the same you know...who would know if something major had happened I might not have felt so in control. I always felt confident in dealing with everything and didn’t really need much help.” (Interview 2)</p> |

Table 11.17: Perceptions of personal control amongst those patients in the merged analysis reporting a medium to high degree of control at the beginning and end of their treatment

In addition, the analysis of the merged data revealed that patients who reported medium and high perceptions of treatment control in the quantitative analysis of the treatment control

subscale of the IPQ-R also identified positive perceptions of the necessity and efficacy of the chemotherapy treatment, being supported, supervised and instructed by health professionals, and their positive perceptions of the future in light of this, within the qualitative analysis of the semi structured interviews. Some examples of these perceptions from the qualitative data are shown in Table 11.18.

| Case | Quantitative Score at start and end of treatment (treatment control) | Excerpts from the qualitative data at beginning and end of treatment |
|------|--|--|
| 1 | High/Med | <p>"There may be things that you should be doing or medication you should be taking beforehand, if that's the case, I expect the professionals to tell me that I'm doing the right thing as it's happening. If it's something they cannae predict, then I'm wasting my time trying to second guess it, I'll nae bother." (Interview 1)</p> <p>"It's the last treatment and I'm pleased to have it over and done with and hopefully we'll get back to a kind of normal life so I'm looking forward to it being finished. Hopefully everything will go the way it should. I'm sure we'll get away for another wee holiday. I might even decide to retire in January." (Interview 2)</p> |
| 2 | High/High | <p>"If that's the way I've got to have hopefully a cure, then I've got to accept that." (Interview 1)</p> <p>"I think I'm a bit cautious with being on chemo. I'm aware that the chemo is a poison going through my system, and I don't want anything to interfere with that...I prefer to ask rather than just go with what somebody else says you know. I was just quite happy to do what they[the health professionals] said because they know best." (Interview 2)</p> <p>"I'll recover, I'm looking to the future now. Once I get the results of the scan, I'll be able to then try and start and live life as normal." (Interview 2)</p> |
| 11 | High/Med | <p>"Everybody's got their own way of adjusting I suppose...I would just speak to that girl [the nurse] up at [the hospital]...she's the one that's been through it before with different other people and I suppose her experience, a wee bit of it might pass on to me." (Interview 1)</p> <p>"If I'm okay in myself then I'll be back at work in six weeks, I want to get back into the swing of things." (Interview 2)</p> |
| 12 | High/High | <p>"I believe I'm in the hands of the specialists and whatever the specialist thinks they'll do is the answer, there's no way I'm going to argue against what the specialists decide." (Interview 1)</p> <p>"The treatment's there to try and save my life you know...it's got to be done if you want to try and survive." (Interview 1)</p> |
| 17 | High/High | <p>"I don't have control over it...the nurses and the doctor were in charge of what was happening. The [doctor] reduced my dosage because I had diarrhoea that was quite severe at that time and that helped, but no I've not had a great deal of control." (Interview 1)</p> <p>"I'm looking forward [the future]...[my wife] is looking forward to getting a holiday too cos we've not had a holiday this year." (Interview 2)</p> |
| 19 | Med/Med | <p>"My mouth was that bad I couldn't clean my teeth, it was that painful but obviously what you do it go to the doctor." (Interview 1)</p> <p>"I've accepted things...I feel fine...I feel totally normal." (Interview 2)</p> <p>"As far as the treatment goes, apart from hanging about waiting to see people it wasn't any bother at all...it wasn't as bad as I thought it was going to be." (Interview 2)</p> |
| 22 | Med/High | <p>"There are people, if I worry about anything, I can phone about it." (Interview 1)</p> <p>"I have confidence in [the doctor] what he said is that he has got all the cancer and it has gone and I also accepted what [the doctor] said that this [the chemotherapy] is a precaution. I accept that this is short term...the side effects are something I've got to endure." (Interview 1)</p> <p>"I'm not somebody that runs to the doctor for every wee thing but I know when I need something and I know if I'm being sick all the time, I need something for that and I know if I've got dreadful mouth ulcers and I can't eat, I need to get something for that so the professionals are the first person I'd do to." (Interview 2)</p> |
| 24 | High/High | <p>"I know this isn't going to go on forever and I will get back to my own fitness I feel that I'm doing something and the treatment is going to work. It's a small price to pay." (Interview 1)</p> <p>"I'm desperate to get back to work...I miss my job so much. I want to take steps forward from now on." (Interview 2)</p> |

Table 11.18: Perceptions of treatment control from the qualitative analysis amongst those patients in the merged analysis reporting a medium to high degree of control at the beginning and end of their treatment

In contrast to the quantitative analysis of the personal and treatment control subscales, which identified that all patients who were included in the merged analysis reported medium and high perceptions of personal and treatment control, the analysis of the qualitative interviews identified that there were fluctuations between individuals' perceptions of control, with some patients reporting a higher degree of personal and treatment control than others during their treatment. Namely, higher perceptions of personal control were particularly evident in the transcripts of patients 1, 12, and 24. In their transcripts, these patients spoke with more determination, and used terminology such as, 'control', before these had been introduced to the interview by the researcher. Patient 12, in particular, reported a high perception of personal control at the beginning of treatment (score of 30.0) in the quantitative analysis of the IPQ-R and in the qualitative data spoke defiantly of his determination to survive and beat the cancer, and his desire to take control over his self care decision making, even if this meant contravening the advice given to him by health professionals. Table 11.19 exemplifies this.

| Case | Quantitative score at start/end of treatment (personal control) | Excerpts from the qualitative data at beginning and end of patients' treatment |
|------|---|--|
| 12 | High/High | <p>"I was determined to survive...I intend to survive and I will survive. After that [the treatment], as far as I'm concerned, I'll be cured and that's how I look at it." (Interview 1)</p> <p>"I've got my mind set and the time March comes next year and I finish treatment, that'll be me...nothing worth bothering about more than making sure you're going to survive at the end of the day." (Interview 1)</p> <p>"That's how I've coped with everything in life...never let anything beat me and so I don't intend to let this beat me." (Interview 1)</p> <p>"I was fortunate that I discovered certain things that I wasn't happy about so I went and seen about it." (Interview 2)</p> <p>"I'm taking control of it [the treatment] that's the name of the game." (Interview 2)</p> <p>"I know more than a lot of folk. Everyday I'm looking after myself." (Interview 2)</p> <p>"That's me taking the decision. I know the doctors say five times a day and all this. I only take it [medication] when I need it...when I think it's going to benefit me. That's how I went through it [the treatment] just making a judgement myself." (Interview 2)</p> |

Table 11.19: Perceptions of personal control reported by patient 12 in the qualitative and quantitative data at the beginning and end of treatment

Furthermore, the analysis of the qualitative interview transcripts of patients 1, 12, and 24 revealed that control may have been considered by them to be an important construct in their lives. These transcripts revealed that for several of these patients, their personal control was derived from a desire to maintain a degree of control that they had perhaps assumed all their lives, as demonstrated in Table 11.20.

| Case | Quantitative score at start/end of treatment (personal control) | Excerpts from the qualitative data at beginning and end of patients' treatment |
|------|---|--|
| 1 | High/High | "You know you can sit back and watch the World go by if you like – it's not in my nature, it never has been, I mean you'll never achieve anything." (Interview 1) "I like to achieve. I hate a day when you haven't done anything or achieved something – it's a total wasted day. I like to plan my day...always have one or two things that I want to get done...something achievable." (Interview 1) |
| 12 | High/High | "I've always been a strong person." (Interview 2) "I've always been a determined swine and I make the decisions at the end of the day." (Interview 2) |
| 24 | High/Med | "I was obsessive about lots of things before...and I felt as if I had to prove something that I was supermum." (Interview 1) "I'm quite a strong person anyway and I'm quite sensible I know about decision making and things like that. If I'd have constantly had to ask advice about things...it'd have made me feel that someone else was running my life. I know my body, I know my limitations and the decisions I can make." (Interview 2) |

Table 11.20: Perceptions of the importance of personal control as highlighted in the qualitative data at beginning and end of treatment amongst patients in the merged analysis

There were other patients in the merged analysis however, for example, patients 11, 17, 22 who reported medium and high perceptions of personal control in the quantitative data, yet their qualitative interview transcripts did not support this, revealing that they perceived themselves to have little control. They spoke with uncertainty and commented on their lack of control over self care, highlighting their reliance on medications and health professionals. Table 11.21 contains some excerpts from their transcripts which illustrate these perceptions.

| Case | Quantitative score at start/end of treatment (personal control) | Excerpts from the qualitative data at beginning and end of patients' treatment |
|------|---|---|
| 11 | High/Med | <p>"It's difficult taking it all in...it does build up a wee bit but I'm not too bad." (Interview 1)</p> <p>"I think you've only got two options...medication, and if that doesn't work then seek advice." (Interview 1)</p> <p>"The side effects, I'll wait for them....and as I say if I've got a problem, she [the nurse] is the kind of person who can help me out and that's it." (Interview 1)</p> <p>"It's just the fourth, fifth and sixth one that sort of brought me down a wee bit you know...a wee bit more "what will I do"...I've got these pills here I just take for diarrhoea, 'what will I do for nausea', I'll just take these oils and if I felt that these werenae working, I'd just phone [the nurse]." (Interview 2)</p> |
| 17 | High/High | <p>"I've got treatment there if I've got any diarrhoea or anything...I can get remedies for anything that happens to me." (Interview 1)</p> <p>"I don't feel I'm isolated in any way...the district nurses are on call if there's anything...I've got all their phone numbers and can probably get one at a moment's notice." (Interview 1)</p> <p>"I don't think I've got control over it [the treatment and self care]. The nurses and the doctor were in charge of what was happening. I don't know if I was really in control over the course of treatment." (Interview 2)</p> |

Table 11.21: Perceptions of lack of personal control over self care as highlighted in the qualitative data at the beginning and end of treatment amongst patients in the merged analysis

11.7.2 Changes in Perceptions of Control Over Time

The quantitative analysis of the full sample (n=24), presented in Chapter 10, highlighted that there were no statistically significant changes in patients' perceptions of personal control but a statistically significant decrease in perceptions of treatment control between the beginning and end of their treatment. Statistical analysis of changes in patients' perceptions of personal and treatment control for the sample of patients included in the merged analysis (n=8) has not been conducted here because the size of the sample limits the meaningfulness of this analysis. However, inspection of the median values, as noted in Table 11.22, for perceptions of personal and treatment control at the beginning and end of treatment in patients' included in the merged analysis, revealed little fluctuation between the beginning and end of their treatment.

| | Beginning of treatment (T1, cycle 1) | End of treatment (T3, cycle 6) |
|-------------------|---|---------------------------------------|
| Personal control | High - 22.5 (19.0-30.0) | High – 21.5 (16.0-23.0) |
| Treatment control | High - 19.5 (16.0-25.0) | High – 19.5 (17.0-20.0) |

Table 11.22: Median values for personal and treatment control in patients in the merged analysis (n=8)

11.8 Involvement in Self Care and the Influence of Control

The previous discussions have highlighted how the qualitative data from the semi structured interviews was particularly useful for contextualising the findings of the quantitative data from the control-related subscales and the self care diary. Subsequently, this chapter has demonstrated the value in using a mixed method approach for offering a rich and in depth understanding of patients’ experiences of their involvement in self care and their perceptions of control. In particular, merging the data sets was valuable for identifying whether the self care carried out by patients was associated with their perceptions of control and whether this influenced the types of strategies that patients carried out during their treatment.

11.8.1 Association of Treatment Control and Self Care

The quantitative analysis of the self care diary and the control-related subscales of the IPQ-R for the full sample (n=24), reported in Chapter 10, identified that there was a statistically significant correlation between patients’ perceptions of treatment control and the degree of self care that they carried out at the beginning and end of their treatment. No statistically significant associations were identified between personal control and the degree of self care carried out by patients at any of the three time points. Hence, as reported in Chapter 10, the quantitative analysis supported the hypothesis that patients with higher perceptions of treatment control carried out a greater degree of self care but this did not relate to perceptions of personal control. However, the relatively small sample size and the cluster of values (representing patients’ perceptions of control and degree of self care carried out) which were observed towards the upper end of the possible range of scores obtained for each variable may have limited the ability to detect this and observe changes between

patients with lower perceptions of personal and treatment control and who carried out a lesser degree of self care.

The findings presented in section 11.8.1 and the excerpts included in Table 11.17 explained some of the possible rationales behind patients' perceptions of treatment control which may also explain the significant association identified with changes in treatment control and degree of self care carried out at the beginning and end of patients' treatment. In particular, the qualitative analysis of the semi structured interviews highlighted patients' strong beliefs in the necessity and efficacy of their chemotherapy treatment and their reliance on health professionals, which was a key self care strategy used at both the beginning and end of their treatment.

Despite there being no further associations found the quantitative analysis of the control-related subscales and the self care diary, as presented in Chapter 9, the analysis of the qualitative interviews identified that patients' perceptions of personal control were indicative of their perceptions towards their involvement in self care. In particular, Chapter 9 demonstrated that patients' perceptions of personal control were seen to be linked with a desire and motivation to be involved in their self care, and also influenced the range of activities that patients carried out as part of their self care during their treatment. Similar findings were seen for the eight patients included in the merged analysis. The following sections consider these findings.

11.8.2 Desire to be Involved in Self Care

The qualitative analysis of the semi structured interviews for the patients included in the merged analysis identified similarities between patients who perceived themselves in the interviews to have higher perceptions of control throughout the course of their treatment. In particular, there were similarities identified between the qualitative transcripts of patients 1, 12 and 24. In particular, these patients shared more positive perceptions towards their

involvement in self care. All three patients identified that their involvement in self care was important in helping them to stay positive, helping them to focus on surviving the cancer, helping them to achieve the goals that they set for themselves, and important for maintaining a sense of normality and preserving their sense of identity. The data identified that these patients also spoke of a greater desire to actively take charge of their own self care. In addition, patients 12 and 24, in particular, demonstrated greater use of the personal pronoun within their transcript which may also indicate their higher perception of personal control over their self care. Table 11.22 demonstrates some of these perceptions.

| Case | Quantitative score at start/end of treatment (personal control) | Qualitative perception during treatment | Excerpts from the qualitative data at the beginning and end of patients' treatment |
|------|---|---|--|
| 1 | High/High | High | <p>"self care is only doing what you've got to do to get on with your life at that stage and as much as you can do." (Interview 1)</p> <p>"you can sit back and watch the World go by if you like, but it's not in my nature, it never has been, I mean you'll never achieve anything. You've just got to do it as far as I'm concerned, there's no other choices." (Interview 1)</p> <p>"I like to plan my day...always have one or two things that I want to get done and it's something achievable." (Interview 2)</p> <p>"Just [having] some sort of goal to aim at [helps]...these things are within your own control...it's nice to have aims and goals that you set and go and do." (Interview 2)</p> |
| 12 | High/High | High | <p>"I've never let anything beat me and I don't intend to let this beat me." (Interview 1)</p> <p>"[self care] is important. I've got to control it...I do control it." (Interview 1)</p> <p>"I've controlled it right from the start. One cannot change their lifestyle, actually I'll not be trying to change my lifestyle, I've become so determined to it." (Interview 2)</p> <p>"You can't just lie back. I'm relying on these people [health professionals] to make me survive, I've got to be careful with them as well, I'm going to have to watch what's happening [to me]." (Interview 2)</p> <p>"I'm taking control of it, that's the name of the game." (Interview 2)</p> |
| 24 | High/Med | High | <p>"I'm a really positive person, I just thought I'll throw everything at this right at the start and then I can get on with my life." (Interview 1)</p> <p>"I just get out, I'm always on the go, it's just the way I live my life." (Interview 1)</p> <p>"[self care] suits me because I don't want to be around hospitals as a patient any more than I have to. I'm happy to go away with this knowing that I will get them [side effects] next week but I know that this is fine and that I'll cope with it." (Interview 1)</p> <p>"I'm quite a strong person and I'm quite sensible. I know about decision making and things like that. If I'd had to constantly phone up and ask advice about things, I think I'd have felt...it'd jut have made me feel that someone else was running my life." (Interview 2)</p> |

Table 11.23: Perceptions towards taking control over self care in patients in the merged analysis with higher perceptions of control (as determined in the qualitative data)

The qualitative analysis of the interviews also identified similarities between those patients who were regarded in the qualitative data as generally having lower perceptions of control throughout the course of their treatment. These patients included, patients 11, 17 and 22. Although patient 22 spoke of her desire for a high degree of control in the qualitative data, her interview transcript also revealed that that she perceived herself to have a low degree of control. In particular, these patients shared similar perceptions of the lack of importance of

their involvement in self care, in contrast to the patients with higher perceptions of control. Furthermore, they also seemed not to expect to play a role in their self care and symptom management, perceiving that health professionals were the experts in relation to this rather than themselves. In contrast to the patients with higher perceptions of control, the patients with lower perceptions of control were more likely to perceive that they could do little to manage the physical impact of their treatment and were more likely to doubt their abilities to carry out self care and to doubt the efficacy of their self care efforts. Some excerpts from the qualitative data in Table 11.23 highlight these perceptions.

| Case | Quantitative score at start/end of treatment (personal control) | Qualitative perception during treatment | Excerpts from the qualitative data at beginning and end of patients' treatment |
|------|---|---|---|
| 11 | High/Med | Low | <p>I would try the things that they've given me first [medications] and then obviously if that didn't help me then I'd get in touch with [a health professionals].” (Interview 1)</p> <p>“They're the people with experience and things like that in situations like that and I think they'd be able to give good advice on that.” (Interview 1)</p> <p>“I might get something wrong again and I'd get in touch with somebody a wee but more experienced.” (Interview 1)</p> <p>“I think you've only got two options of medication, and if that doesn't work then seek advice [from health professional].” (Interview 1)</p> <p>“I just take these pills, and if I felt that these weren't working then I would phone the team.” (Interview 2)</p> |
| 17 | High/High | Low | <p>“I can get remedies for anything that happens to me...get to see my own GP for problems...and I'm only ten minutes away from the [hospital] if anything serious crops up.” (Interview 1)</p> <p>“I don't have control over it [the side effects]...the nurses and doctor were in charge of what was happening. She reduced my dosage because I'd had diarrhoea that was quite severe....but no, I've not had a great deal of control.” (Interview 2)</p> |
| 22 | Med/High | Low | <p>“Although you do the self care things, there's a feeling that sometimes you can't do anything about the side effects. I don't feel totally in control of some of the things you know I do the best I can to help with it but I'm aware that things can flare up so no I don't have total control over it.” (Interview 1)</p> <p>“The side effects are something I've got to endure.” (Interview 1)</p> <p>“I have no control over what the next side effect will be and things like that and a lot of the things you do to try and prevent it, don't prevent it happening and you take stuff and you think that will help and you're not convinced that it has.” (Interview 1)</p> <p>“I didn't feel great but I felt I knew I could get the antisickness tablets, mouthwashes and things like that but I started to dread each month because despite the fact that I knew I could get these things, I know I would have the symptoms anyway so I knew that they would alleviate it a little but they wouldn't stop it so I don't think I had huge confidence in those things.” (Interview 2)</p> <p>“What I did was if I felt sick, and I wanted stronger antisickness [tablets], they'd give me stronger ones and if my mouth ulcers were really bad, I'd keep going bacon and keep going back to them and ask them for more and more.” (Interview 2)</p> <p>“I know if I've got dreadful mouth ulcers and I can't eat that I need something for that so the professionals are the first person I'd go to to get some medicine.” (Interview 2)</p> |

Table 11.24: Perceptions towards not taking control over self care in patients in the merged analysis who had lower perceptions of control (as determined in the qualitative data)

11.9 Overall Summary of the Merged Data Analysis

In response to the gaps identified amongst previous research on the involvement of patients with cancer in self care, the current study set out to explore how a mixed method, longitudinal approach could contribute towards a greater understanding of patients' perceptions and experiences of self care. The approach adopted in this study combined the findings from qualitative and quantitative analyses in helping to expand the breadth and range of this investigation into patients' involvement in self care and their perceptions of control during treatment for colorectal cancer. Interestingly, although the quantitative analysis of the self care diaries revealed little significant changes in the degree of self care and the types of self care activities that were carried out by patients between the beginning and end of their treatment, the qualitative analysis of the semi structured interviews found that patients' involvement in self care did change in terms of the types of self care activities that patients carried out as part of their self care (as noted in Chapter 9). In particular, there was a change seen in patients' use of emotional self care strategies, for example, rationalising and comparing and focussing on the future were strategies which were used to a greater extent at the end of treatment compared with the beginning of treatment. There was also evidence within the qualitative interviews of a greater range of 'adaptive' strategies being used towards the end of patients' treatment, in particular, patients made more dietary changes and made attempts to try and regain their physical fitness to compensate for the cumulative impact of fatigue on their lives.

The qualitative analysis of the semi structured interviews was particularly valuable when compared with the quantitative analysis of the control-related subscales and self care diaries since it revealed important differences between the data sets and in particular, was able to identify different aspects of patients' perceptions and experiences of their involvement in self care that the quantitative analysis had been unable to detect. In particular, the qualitative semi structured interviews were able to identify a greater range of physical self care strategies used by patients, for example, relying on health professionals, and also the

emotional self care strategies that they used to manage the emotional, rather than the physical, impact of undergoing treatment for cancer, than had been identified in the quantitative self care diary. Furthermore, the quantitative self care diary identified that patients rarely used medication and rarely made dietary changes in managing the physical impact of their treatment, whilst the qualitative analysis of the interviews revealed opposing findings. Partly, as previously mentioned, this may have been due to the conceptualisation of self care used to frame the study and the structure of the self care diary, however, it may also have been due to the nature of the different approaches to data collection, being able to explore the different levels and facets of patients' perceptions and experiences of their involvement in self care.

Comparison of the qualitative and quantitative data sets was also valuable for exploring patients' perceptions of control, accurately assessing how these changed, and for identifying the rationales underlying their perceptions of control. The quantitative analysis of the control-related subscales suggested that there were no significant changes in patients' perceptions of personal and treatment control between the beginning and end of their treatment. The quantitative analysis of the control-related subscales also suggested that patients consistently reported medium and high perceptions of control between the beginning and end of their treatment. When merged with the qualitative analysis of the semi structured interviews, however, the findings suggested that there were in fact some patients who perceived themselves to have a low degree of personal control during their treatment. The qualitative analysis of the interviews were particularly valuable for identifying possible rationales behind these perceptions.

Comparison of the qualitative and quantitative data sets helped to explore similarities between the perceptions and experiences of self care in patients with higher and lower perceptions of control and identify how patients' perceptions of control were associated with their attitudes towards self care and the self care activities that they carried out during

their treatment. Furthermore, the qualitative analysis of the semi structured interviews helped to offer some insight into why there was a significantly positive association between patients' perceptions of treatment control and the degree of self care that they carried out at the beginning and end of their treatment. Subsequently, this chapter has highlighted the value of a mixed method, longitudinal approach, over a purely quantitative or qualitative approach, in conveying the uniqueness of patients' perceptions and experiences of control, self efficacy and involvement in self care and thus, has enabled a rich, accurate, and detailed understanding of patients' involvement in their self care.

Chapter 12 Discussion

12.1 Introduction

The current study, which was grounded within Leventhal's Self Regulation Model, set out to explore patients' perceptions and experiences of their involvement in self care and their perceptions of control and self-efficacy whilst undergoing treatment for colorectal cancer, and to determine how these changed throughout a six-month course of chemotherapy treatment, using a longitudinal, mixed method approach. The following chapter begins with a summary of the principal findings from the study and a critical consideration of the strengths and weaknesses associated with the methodology adopted in this study. The principal findings from the study are then discussed in detail with reference to the wider literature and existing research before finishing with a discussion on the relevance and implications of these findings for clinical practice, theories relating to self care and future research.

12.2 Summary of Key Findings

The principal findings in this study demonstrated that self care held a range of meanings to the patients in this study and in particular, consisted of two components; physical self care, carried out to manage the physical impact of undergoing treatment, and emotional self care, carried out to manage their emotional response to being diagnosed with, and undergoing treatment for, cancer. The findings demonstrated that there was no association between patients' perceptions of control and the degree of self care that they carried out identified in the quantitative analysis. However, in the qualitative analysis, it was revealed that patients' perceptions of control were likely to influence their attitudes towards their active involvement in self care and the importance with which they viewed this role. In particular, patients who considered themselves to have a high degree of control during their treatment were more likely to believe that they could limit the impact of the treatment through their own actions, that being actively involved in their self care was important and were interested in taking on this role, and that they would use a greater range of self care

strategies in helping to manage the impact of their treatment. Conversely, patients who considered themselves to have a lower degree of control during their treatment were less likely to believe that they could limit the impact of the treatment through their own actions, that their active involvement in self care was important and were less likely to expect to take on an active role, preferring to leave the management of treatment-related effects to health professionals, whom they regarded as being the “experts”. The later sections of this chapter consider these findings in further detail and in particular, their importance and relevance to existing research that has been conducted in this field. The following section, however, firstly considers the methodology used in this study and whether it met its’ intended aim of offering a greater understanding of patients’ involvement in self care through combining both qualitative and quantitative approaches.

12.3 Critique of the Methodology

In this study, the researcher attempted to explore perceptions and experiences of being involved in self care and perceptions of control and self efficacy in a homogenous sample of patients undergoing a six month course of chemotherapy treatment for colorectal cancer. A longitudinal design combining qualitative semi structured interviews with quantitative diaries and questionnaires was employed to obtain a rich and in depth understanding of the uniqueness of patients’ perceptions and experiences of their involvement in self care. This design was also followed to explore changes in the degree of self care that patients carried out and patients’ perceptions of control and self efficacy between the beginning and end of their six month course of treatment. The aim of this design was to combine both qualitative and quantitative approaches for the purposes of complementarity and expansion (Greene et al, 1989; Brannen, 2005) to explore different research questions relating to a particular phenomena and to combine both sets of findings in a way that was mutually illuminating. In particular, a qualitative approach was employed to explore the lived experience of being involved in self care, to describe the types of self care activities people carried out during their treatment and their attitudes towards their involvement in self care. In

complementing, contextualising and expanding upon these findings, a quantitative approach was employed to quantify, and determine associations between, changes in the degree of self care and the types of self care activities carried out by patients and their perceptions of control and self efficacy between the beginning and end of their treatment. The underlying logic of this design was to combine both the qualitative and quantitative findings to offer a greater understanding of patients' involvement in self care than one approach alone would have been able to offer which is believed to be a key strength of using a mixed method design (Morse, 2003; Tashakkori and Teddlie, 2003). Furthermore, it is an approach which is commonly employed when a portion of the phenomena can be measured and used to aid interpretation of the qualitative data.

The complementary nature of the findings that were produced by both methods in this mixed method study demonstrated that this aim was in part achieved. For example, firstly, the qualitative findings revealed the range of both physical and emotional self care activities that were carried out by patients during their treatment, whilst the quantitative findings identified that the patients in this study carried out a high degree of self care at all time points between the beginning and end of their six month course of treatment. Secondly, although the qualitative findings suggested that patients' perceptions of control were indicative of the likelihood that they would be actively involved in their self care and the importance with which they viewed this role, the quantitative findings did not identify an association between the degree of control that patients' perceived themselves to have between the beginning and end of their treatment and the degree of self care that they carried out both at the beginning and end of their treatment. Hence, these findings appeared to suggest that perceptions of control did not influence the *degree* of self care that was carried out by patients but did appear to influence patients' *attitudes* towards self care. These are essentially the principal findings from this study and can be considered complementary rather than divergent since they each reflect a different view of patients' involvement in self care. The primary purpose of this section is to further consider the

findings that were produced by both the qualitative and quantitative methods and the limitations of these by critically examining the nature of both approaches, reflecting on their implementation, and considering the complementarity of the findings and possible explanations for this. This is important in order to understand the complexities and challenges involved in researching patients' involvement in self care but also more generally to enhance the robustness of the study and facilitate an accurate interpretation and explanation of its findings (Moffatt et al, 2006).

Both the qualitative and quantitative approaches set out to explore different aspects of the same phenomena, namely, patients' involvement in self care hence, both intended to answer different research questions. In particular, this is highlighted when looking at the questions relating to patients' *perceptions* of self care (research question 1) and the *degree* of self care that they carried out (research question 2). In addressing the first research question, the qualitative approach was used to explore patients' perceptions of what they did as part of their self care and subsequently, highlighted the wide range of self care activities that patients carried out. In addressing the second research question, the quantitative approach set out to determine the degree to which patients carried out self care, revealing that they had carried out a high degree of self care. Therefore, it may be unsurprising that that both approaches produced different yet complementary findings and these quite rightly should, according to Moffatt et al (2006), be considered to be complementary rather than divergent since each set of findings reflects a different view of patients' involvement in self care.

It could be argued, however, that the complementary nature of the findings from the qualitative and quantitative data sets were a result of the theoretical paradigms and the subsequent nature of these approaches (Chesla, 1992), as well as their particular strengths and weaknesses. Generally speaking, qualitative research can be said to be relatively unstructured, allowing participants to freely speak in their own words and allowing cues to be probed for further detail and discussion by the researcher. In this study, the semi-

structured nature of the qualitative interviews allowed participants to freely speak of all that the terms ‘self care’ and ‘control’ meant to them and all that they did as part of their self care and allowed the researcher to probe for further detail or clarification on these issues. This is in comparison to quantitative data collection methods which are far more structured, curtail patients’ responses and typically allow little opportunity for free text and for probing by the researcher (Bryman, 2004). Thus, the structured nature of the quantitative self care diary in this study, for example, may have achieved its purpose of standardising patients’ responses, yet it offered little opportunity for patients to respond in their own words and no opportunity to probe patients’ responses further.

Hence, encouraging patients to give their own perspective enabled them to not only speak of what they *did* as part of their self care but also their *attitudes* towards their involvement in self care (and their perceptions of control). As a result, this offered an insight into the relationship between control and self care from this perspective. The qualitative approach could, therefore, be considered as being patient-led since its findings were driven by the patient’s own perspective, whilst the quantitative instruments being devised from the perspective of the investigator or academic, cannot be considered patient-led. Subsequently, the quantitative instruments may have failed to adequately capture patients’ true perceptions and experiences that may have emerged in the qualitative findings. This dilemma was clearly highlighted in the current study whereby the qualitative findings revealed self care to have both physical and emotional components (offering the patients’ perspective) yet the quantitative self care diary measured physical self care only (derived from the academic’s perspective). Subsequently, the design of this instrument if used alone, could have limited the achievement of a fuller, more realistic understanding of patients’ self care and all that this comprises. Existing self care diaries, such as Nail et al’s (1991) self care diary, that have been frequently used in previous research, may also limit this understanding because of their structured nature and the use of a predetermined list of self care behaviours contained within these instruments.

Given that the quantitative instruments used to measure control and self efficacy were also investigator/academic-generated, they too may have failed to adequately capture patients' perceptions of their control and self efficacy, an issue that was noted in Chapter 4 as contributing to the lack of theoretical and empirical clarity on the construct of control and control related terms. For example, the Revised Illness Perceptions Questionnaire (Moss Morris et al, 2002), which was used to measure perceptions of control, asked about perceptions of control in relation to the illness itself as opposed to managing the effects of the treatment and feeling in control of these, i.e. "I have the power to influence my illness" and "the course of my illness depends on me." Yet, in the qualitative interviews, patients' spoke of their perceptions of control over the management of treatment-related side effects and their emotional wellbeing rather than their perceptions of control over the course of the cancer itself and preventing recurrence. Hence, what these findings demonstrate is the mismatch between patients' and investigator/academic's perceptions of these constructs and thus, the challenges of accurately capturing and measuring constructs such as, self care and control using quantitative approaches alone and question the utility of existing measures. There may, therefore, be a need for revised instruments that are derived from the patients' perspective, and of particular relevance to the focus of this study, instruments that encapsulate the different dimensions of patients' self care and their perceptions of control over managing '*the impact of treatment*' as opposed to '*control over the disease*' and other entities.

In discussing the complexities and challenges involved in accurately capturing patients' perceptions and experiences of self care, control and self efficacy using existing measures, it is important to explore the difficulties that were encountered in using a qualitative approach in this study. In particular, there was little depth to the information obtained from patients on their perceptions of self efficacy, meaning that these could not be adequately compared with the quantitative findings on perceptions of self efficacy. It could be argued that although questions around self efficacy were included within the interview guide and

posed to patients during the interviews, the interview guides may have been too closely structured around Leventhal's Self Regulation Model, and hence, this and the issue of control was most concentrated on as opposed to the questions around self efficacy. It may also have been because patients experienced difficulties in distinguishing between the constructs of self efficacy and control, which were discussed in Chapter 4 (Strecher et al, 1986; Ajzen, 1991; Thompson and Spacapan, 1991; Thompson and Collins, 1995; Skinner, 1996; Griva et al, 2000; Ajzen, 2002). As a result, patients did not seem to speak of their perceptions of self efficacy, but rather spoke of their perceptions of control. Bearing this in mind, the researcher could have probed further on these issues and clarified their nature for patients, however, the patients' perspective was the focus of the semi structured interviews and, therefore, a tension existed between allowing this perspective to come through in full or clarifying the nature of self efficacy so that what was obtained was actually the researcher's perspective as opposed to the patients' perspective. This is a commonly experienced dilemma in qualitative research (Kvale, 2007).

Another challenge in the qualitative approach was the absence of a 3rd interview at the mid point of patients treatment which would have aided linkage between the qualitative and quantitative at each of the three time points, as opposed to just at the beginning and end of patients' treatment. In particular, the absence of a third interview being conducted with patients at the mid point of their treatment (to match the quantitative data collection procedure) would have been useful in order to capture changes in patients' perceptions and experiences at this point in their treatment journey. This is particularly pertinent given the findings of the quantitative analysis which found a statistically significant increase in the degree of self care carried out by patients between the beginning and middle of their treatment and it would have been valuable to qualitatively explore possible explanations for this finding.

Secondly, in evaluating the use of the mixed method design in this study, it is important to question why there were no measurable changes seen in the quantitative findings in relation to increases in patients' perceptions of control and self efficacy over the duration of their six month course of treatment. Given the exploratory nature of this study and the inductive theoretical drive, the quantitative approach was intended to allow the variables to be measured over time with precision, as noted by Anderson (2003) and to allow these changes to be more easily observed, as opposed to being used for hypothesis testing and generalisability purposes per se. The lack of measurable changes over time seen in this study, however, may have been a result of several issues. In particular, the relatively small sample size in the quantitative component in this study limited the representativeness of the sample and reduced the power with which to detect statistically significant changes over time (Bowling, 2002). It is believed that the larger a sample size is, the greater likelihood that the sample will be precise, i.e. as sample size increases, sample error decreases (Bryman, 2004). Subsequently, any statistically significant changes that were identified (for example, in the degree of self care carried out by patients between the beginning and middle of their six month course of treatment) that were found have to be treated with caution.

The sampling frame may have contributed to the small sample size. It was intended that a homogenous sample of patients receiving one specific type of chemotherapy regimen for colorectal cancer would be recruited as this would limit the influence of extraneous variables such as, tumour and treatment type, on the variables of control, self efficacy and involvement in self care. This approach, which was determined at the outset of the study (and confirmed as being appropriate following the initial pilot study that was conducted which was before any recruitment challenges were known), subsequently proved to be challenging because of the commencement of new clinical trials at the clinical site which coincided with the start of data collection. As a result, this significantly reduced the number of potentially eligible participants and hence, exacerbated the recruitment

difficulties experienced during the study (as discussed in greater detail in Chapter 7). Although several strategies were employed to counteract the difficulties experienced, the reduced number of potentially eligible patients had implications for the final sample size and its representativeness and the statistical power for the quantitative component.

Another sampling issue related to the longitudinal design of this study was the issue of attrition (Bowling, 2002). Although the researcher attempted to minimise sample attrition by ensuring that the instruments to be completed by patients were kept simple, and the lag time between data collection time points were fairly short, as noted in the literature (Singer and Willet, 1996; Ruspini, 2000), the longitudinal nature of this study, requiring patients' participation from the beginning to end of their treatment period (6 months), meant that some attrition from the original study sample was inevitable. In total, seven patients withdrew or were excluded from the study. Two patients withdrew because they didn't want to be part of the study any longer and five patients were excluded because they either consented and then failed to return data at the first data collection point and were subsequently excluded from further rounds of data collection (2 patients) or had their treatment discontinued by the clinical team and, therefore, they were no longer eligible to participate in the study (3 patients). Analysis was not carried out on those who dropped out or were excluded, therefore, the study findings may have been influenced by the fact that only data on those patients who were willing or well enough to participate was collected. Indeed, the researcher acknowledges that the perceptions of those patients who dropped out from the study or who did not return completed data at the first time point may have been very different, and thus may have produced a different set of findings (Robson, 2002).

It was also intended that a purposive sampling strategy, selecting participants based on characteristics such as their age, gender, socio-economic status, social support and living arrangements (i.e. being married, living with family or living alone), level of comorbidity and performance status, would be employed. Of these, age (Al-Windi et al, 2000; Reynolds

et al, 2004), gender (Al-Windi et al, 2000), level of comorbidity (Bayliss et al, 2007) and the social context in which one lives, for example, being married and the provision of social support (Ni et al, 1999; Skinner et al, 2000; Kokanovic and Manderson, 2006), have been suggested as having an influence on patients' self care decision making and their subsequent self care behaviours in a range of different patient groups. Had the pool of potentially eligible patients been larger and had the subsequent selection of participants based on the characteristics listed here been possible, it would have ensured that the sample was of a reasonable size and consisted of an appropriate degree of diversity with which to facilitate a detailed exploration and understanding of the variables under investigation taking into account these demographic variables. It has been acknowledged that the greater the diversity within the sample (in terms of demographic characteristics), the more opportunity there is to identify their different contributory elements of influences to the topic under investigation (Ritchie et al, 2003). The characteristics of the sample could not be controlled either and hence, there was too little diversity within the sample to explore the varying influences of factors such as age, gender, socio-economic status (and living arrangements), level of comorbidity and performance status on patients' perceptions and experiences of their involvement in self care and their perceptions of control and self efficacy. In particular, the patients in this study were predominantly patients who had been diagnosed with Dukes' C stage colorectal cancer, had a performance status of zero, had no pre-existing co-morbidities, and lived with their partner or family. As a result of the fewer numbers of potentially eligible patients available a consecutive convenience sampling strategy was subsequently employed in an attempt to limit any further reduction in potential participant numbers and, therefore, to ensure that as many remaining patients as possible who were offered the Mayo Clinic Regimen were approached to consider taking part in the study. Consequently, in using this approach, no claims can be made about the representativeness of the sample (Bryman, 2004) and the perceptions of patients with different stages of cancer, different performance status, co-morbidities, and who live alone

may be very different to those expressed in this study and a limitation of the study is that the influence of these factors could not be explored.

The degree to which changes in the variables could be detected may also have been exacerbated by the particularly high reports of self care carried out and perceptions of control and self efficacy seen at all three time points. As a result, these reports created a ceiling effect which may have limited the ability to detect further changes in the variables over time (Lipsey, 1990), particularly changes in the variables of personal control and self efficacy. Had there been a larger sample and more diversity within patients' reports of the degree of self care that they carried out and their perceptions of control and self efficacy, it may have been possible to observe further changes in these variables over time, as was initially hypothesised. However, another interpretation of the lack of changes observed in patients' perceptions of personal control in the quantitative analysis is that perhaps there may have been little scope for patients' perceptions of control to increase to begin with. This suggestion arises from the fact that the patients in the study reported high perceptions of control in the quantitative data from the very beginning of their treatment (at the start of their participation in the study).

Bearing this finding in mind raises the issue of the accuracy of patients' reports because of the use of self report tools such as in this study, and the implications of this for the study findings. At the most basic level, there are concerns that the use of self report tools can introduce a degree of bias within a study. For example, one might want to create a certain impression and choose to answer in a socially desirable way in order to represent themselves more favourably as opposed to presenting a truth which they may consider would not be socially desirable. Respondents may also fake their answers to make things look worse or better than they actually are. Such biases were identified by Adams et al (1999) in their review of self report methods used to assess adherence to guidelines by clinical staff. There may also be inconsistencies between what people report at different

times across a repeated assessment study (Del Boca and Noll, 2000). Furthermore, using a self report tool contributes to the difficulty in distinguishing between *actual* and *perceived* behaviours and changes (Kazdin, 1999). For example, this may be reflected in one having the perception of feeling in control yet not being in control (Kazdin, 1999). Another example from this study may be the differences between the self care activities that people *reported* that they did and those that they *actually* did. This is particularly relevant given the earlier comment about answering on the basis of social desirability. The patients in this study may have perceived that answering “yes” to carrying out self care was the right answer or the socially desirable answer given the focus of the study. The difficulty with this is that there is no way of knowing what people actually do and it is particularly challenging to know what might constitute an objective measure of patients’ involvement in self care.

There are also implications of the use of self report tools for the accuracy and completeness of the data collected from participants (Bryman, 2004). In particular, the use of self report tools also raise questions about participant recall (Stone et al, 2000), however, a strength of this study was the prospective collection of quantitative data across each of the time points. This avoided the problem of patient recall and meant that the data would have been more accurate (Dowdy et al, 2005). It was evident in this study that a number of the subscales in the quantitative data collection tools, in particular, the self care diary, suffered from missing data (over 40%) and were subsequently excluded from the analysis. These included, for example, the perceived helpfulness of each self care behaviour that patients had carried out, the extent to which they perceived the side effects that they had reported to have bothered them, and the degree of self care they carried out to prevent side effects from occurring. Missing data such as this, is a problem since those people who did not answer a particular question may have very different views from those that did (Robson, 2002). It is difficult to determine whether the extent of missing data was a reflection of the participants within this particular sample and the extent of missing data might have been different in another

sample. Ultimately, however, had these subscales been more complete, it would have aided a fuller analysis of the self care data and would have facilitated a fuller understanding of the rationales for patients' self care behaviour when merged with the qualitative data.

Another limitation of the quantitative instruments was related to the issue of reliability and validity. Whilst the validity and reliability of the questionnaires used (the IPQ-R and the SUPPH) have previously been demonstrated (Horne and Weinman, 2002; Moss Morris et al, 2002; Jopson and Moss Morris, 2003; Whitmarsh et al, 2003; Hagger and Orbell, 2005), the self care diary was developed for the purpose of this study. The diary was developed based on a review of the existing literature on the common side effects caused by chemotherapy for colorectal cancer and self care strategies and relevance and appropriateness of the content of the diary was confirmed by the clinical team at the site where the research was being conducted. Hence, the content validity of the diary was tested. There were, however, no further tests of validity and indeed reliability conducted on the diary used in this study and therefore, the validity and reliability of the diary used here cannot be compared with other self care diaries that have been previously used in studies of self care in patients with cancer (for example, Nail et al, 1991, Richardson and Ream, 1997, Ream, 2002; Ream et al, 2006). Subsequently, the findings from the self care diary should be treated with caution.

In evaluating the mixed method design in this study, it is apparent that there are several explanations to account for the findings that were produced by the qualitative and quantitative components and for the lack of measurable changes over time seen in the control and self efficacy variables in the quantitative component. It is possible that some of these limitations could have been overcome by conducting the research in multiple sites as opposed to a single site, facilitating the recruitment of a larger sample which would have enabled the findings of the statistical analysis to be more confidently concluded and allowed for a more systematic sampling strategy to be employed, rather than one of

convenience as was the end result. It may have been useful to explore the use of an alternative mixed method design, for example, the use of a sequential mixed method design, rather than the concurrent design opted for at the start of this study. The use of a sequential mixed method design may have facilitated a greater degree of follow up of patients' responses to be undertaken. For example, it could have permitted an opportunity to review and analyse the questionnaire and diary data in order to allow the interviews to be far more tailored to these responses (Driscoll et al, 2007) than what was perhaps possible in the study. What's more, it would have enabled patients to be categorised into particular sub groups based on their perceptions which may have helped to facilitate a greater degree of comparison of perceptions between the groups and facilitated a greater degree of follow up of confusing or significant results (Driscoll et al, 2007). The use of a sequential mixed method design may also have allowed a degree of purposive sampling for the semi structured interviews to take place as conducting and analysing the quantitative phase first may have identified important perceptions or characteristics that were particularly relevant and which could have formed the basis for the purposive selection of participants in the qualitative semi structured interviews.

Nonetheless, despite the challenges of finding study design which enables the researcher to accurately capture and understand the complexity of patients' involvement in self care and the limitations of the design employed in the current study, using a concurrent mixed method design in this study has had several advantages. Firstly, it has generated findings on patients' involvement in self care from different perspectives and highlights the role that perceptions of control, in particular, can play in influencing their attitudes towards the likelihood of them actively becoming involved in their self care. These findings, therefore, make an important contribution towards how patients with cancer perceive the meaning of self care, the range of activities that they carry out as part of their self care, and how factors such as their perceptions of control can influence their attitudes towards their active involvement in self care. Such findings are valuable for nurses' clinical practice since they

can be used to understand the complexities associated with patients' involvement in self care, their preferences for being involved in self care and offer a greater understanding of patients' self care responses and the factors that influence these. Further discussion of the implications of the study findings for clinical practice is considered in section 12.6. Secondly, using a concurrent mixed method design has demonstrated the challenges of accurately and realistically capturing the complexity of patients' involvement in self care and the influence of their perceptions of control. Had a single approach been used alone in this study, it would not have uncovered the depth of understanding on patients' involvement in self care that these study findings offer and would not have allowed an understanding of how the strengths and weaknesses of both data sets contributed towards that understanding. In particular, it has demonstrated how different conclusions may have been drawn had, for example, the quantitative approach been used as a single approach in this study and has helped to understand the explanations for the complementary nature of qualitative and quantitative methods in understanding more about patients' involvement in self care. Subsequently, as recommended by Moffatt et al (2006), this level of interrogation of both data sets has helped to enhance the robustness of the study and the interpretations made from the findings of each data set. The implications of the findings in light of this critique of the methodology used are further considered in section 12.8. The following sections firstly explore the study findings in greater depth.

12.4 Involvement in Self Care

12.4.1 Conceptualising Self Care

The qualitative interviews showed that in speaking of how they were involved in self care, patients identified all that they did to manage their physical and emotional responses to the impact of their treatment. In particular, patients spoke of their physical self care as being employed to manage the physical impact of undergoing treatment, for example, treating and adapting to side effects. Emotional self care, was considered as those activities that people carried out in order to help them make sense of their situation, help them to learn what

would happen to them whilst undergoing treatment and to help them to maintain a sense of normality over their lives.

These findings are interesting since they appear to demonstrate the patients' perspective of what self care is and its' meanings as opposed to defining self care from a policy maker or academic's perspective. This is important to note since many of the previous definitions of self care, presented in Chapter 3, have failed to understand the lived experience of self care from patients themselves and often fail to acknowledge the different elements that comprises patients' self care. Indeed, some of the definitions presented in Chapter 3, view self care in a physical sense only. For example, Levin et al (1977, p11) stated that self care is "*the process whereby patients deliberately act on their own behalf in health promotion, prevention of illness and the detection and treatment of health deviations.*" Hence, Levin et al (1977) do little to acknowledge the wider aspects of patients' self care. Similarly although Orem (1995, p104) refers to "well-being" in her definition of self care - "*an adult's continuous contribution to his or her continued existence, health and well-being*" - there is little in this definition to clarify what she means by this, and hence, little to support the view that self care is perceived as having both physical and emotional components. This is perhaps not surprising given that Orem's (1995) Self Care Model was developed as a model to guide nursing care rather than to specifically understand the process of self care, and all that it comprises, from the patients' perspective. The relevance of the study findings to existing theories of self care are further considered in section 12.7.

The same lack of understanding of the physical and emotional components of patients' self care is also demonstrated in the definition of self care that was used to frame this study. At the outset of this study, the researcher based the study on a definition that was specific to patients with cancer as she believed this to be important in order for providing the context for the study and this thesis. The only specific definition identified from the literature on self care in patients with cancer was that proposed by Musci and Dodd (1990, p395);

“patients who practice self care may engage in self observation, recognise and label symptoms, and judge their severity, assess and choose treatment options, and evaluate the effectiveness of their self care.” The implications of adopting this definition as the conceptual basis for the study were discussed in detail in section 12.3, however, it is fair to say that the findings from this study only serve to highlight the inadequacies of this definition and appear to more fully capture how self care is perceived by patients with cancer than previous definitions.

One explanation for the existence of the definitions considered in Chapter 3, may be because of the social and cultural contexts of care which these were referring to. Although, the concept of self care has more recently been recognised as having medical and social connotations (Bury and Pink, 2005, Chambers, 2006), the dominance of the medical model in relation to self care is evident within these definitions by way of their focus on the physical aspects of self care. One definition which does reflect both the medical and social connotations of self care, however, is that proposed by the Department of Health (2005a). In their definition, designed to set the context for current health policy surrounding the management of long term conditions, self care is proposed as *“the actions individuals and carers take for themselves.....to stay fit and maintain good physical and mental health, meet social and psychological needs, prevent illness or accidents, care for minor ailments and long term conditions and maintain health and wellbeing after an acute illness or discharge from hospital”* (Department of Health, 2005a, p5). Elements of this definition are indeed reflected in the findings from this study, however, this particular definition was not available at the start of the study. Furthermore, like the criticism mentioned earlier, this too, also fails to adopt the perspective of self care from the patient themselves and has been devised by policy makers for the purpose of informing current and future health service delivery.

The limitations of failing to adopt a patient perspective in understanding the meanings that patients ascribe to self care are evident in many of the definitions cited earlier since ultimately these definitions often fail to fully capture how self care is perceived by patients themselves and its' elements and, consequently, offer a distorted view of self care. Ultimately, the importance of this relates to the earlier discussion in Chapter 3 around the implications of understanding perceptions of, and attitudes towards, self care. In particular, the earlier chapter on self care (Chapter 3, section 3.5.2) highlighted that to date there has been little emphasis on adopting a patient focus within existing theories relating to self care and previous research and health policy relating to self care. Hence, little is known about patients' true perceptions towards their involvement in self care.

Previous research has also suggested that patients perceive there to be little opportunities and support provided to them by health professionals to help them actively engage in their self care (Sims, 1999; Scotto, 2005). The lack of an understanding of self care from the patients' perspective may have contributed to such findings. Subsequently, how can patients be enabled to carry out self care and practitioners encouraged to support patients' involvement in self care if there is little understanding as to how self care is perceived and understood by those who are involved in it. The findings from this study, therefore, help to reinforce the importance of understanding the patient's experience and their attitudes towards, and involvement in, their self care. The importance of this and its' implications for nursing practice are further discussed in section 12.6. The following section considers the findings in relation to the nature of the activities that comprised patients' physical and emotional self care in further detail and in particular, the importance of these findings and their relevance to previous research.

12.4.2 Self Care As a Whole

The findings from this study were valuable for understanding more about what patients with cancer did as part of their physical and emotional self care whilst undergoing chemotherapy

treatment. In speaking of their physical self care, patients spoke of activities that were principally employed to manage the impact of their treatment. These included, treating side effects with medications and mouthwashes, and finding ways to adapt to, or compensate for, effects such as fatigue. Despite this study focussing only on patients with colorectal cancer, there is evidence from the literature that similar self care activities have been carried out by patients with different tumour types during treatment for cancer, for example, in studies including patients with breast, ovarian, colorectal and lung cancers (Dodd, 1988; Richardson and Ream 1997; Borthwick et al, 2003). Quantitative studies by Dodd (1988), Nail et al (1991), Foltz et al (1996) and Borthwick et al (2003) have previously identified that common self care activities carried out by patients in managing the impact of cancer-related fatigue included, sleeping, taking naps and resting. Similarly, in a quantitative study using structured diaries, Richardson and Ream (1997) identified that patients (n=109) managed the impact of cancer-related fatigue through resting and napping, taking things easy, modifying activities and employing relaxation techniques. In a smaller quantitative study of the management of radiotherapy-related mucositis (Wong et al, 2006) in patients (n=49) with head and neck cancer, taking medications and using mouthwashes were the most frequently carried out self care activities reported by patients.

Such activities can be likened to the 'medical model', in which health is defined as the *absence* of disease and ill-health as the *presence* of disease and is driven by the belief that medical treatments must be sought and applied in order to return to full health. The side effects caused by the chemotherapy treatment are in essence the focus of this component of patients' self care, rather than the person as a whole and their interaction with the World around them. However, the medical model has not been without its' critics and because of its' dominance on medical specialism, has created a cycle of dependency on professionals because they have final authority over the treatment of illness (Anderson, 1995; Craddock and Reid, 1999). This may offer one explanation as to why the theme 'relying on health professionals' emerged so strongly in the qualitative data. Within this theme people spoke

of not being experienced enough to be actively involved in their own self care, that they might not know what to do or get something wrong and have to bare the consequences of this, and they shared a commonly held belief within wider society that health professionals were the experts and had spent years training to be in the position whereby they can recommend the best treatment options or the best advice.

These findings offer support for the findings from a study in patients with asthma (n=24) which demonstrated a similar reliance on the medical model and thus, health professionals (Koch et al, 2004). In this study, Koch et al (2004), identified that the epitome of patients' management of asthma was following doctors' orders and taking medications (similar to the findings of the current study). Interestingly, however, there is no previous work on self care in patients with cancer has identified 'dependency on health professionals' as being a self care option for patients. This may be for a couple of reasons. Firstly, it may be that other researchers fail to include dependency on health professionals as a self care activity since by its' very nature it seems at odds with patients' own active involvement in self care. However, it was a key theme generated from the qualitative analysis in this study when patients were asked about what they did as part of their self care and hence, was considered to be essential in identifying the meaning of self care from the patients' perspective and understanding more about their subsequent involvement in self care and thus, was included in the findings. Secondly, the finding of dependency on health professionals may have emerged as a result of the qualitative approach that was incorporated into this mixed method study, which is in contrast to the quantitative nature of much of the existing work on self care in patients with cancer, and as a result, by using this approach it meant that patients were not curtailed by a standardised list of responses (as they were in the self care diary) and could freely give more detailed responses as to what their self care activity comprised.

Thus so far, this discussion has revealed that the findings from this study support existing work on self care in terms of the physical self care activities that patients carried out in managing the physical impact of their treatment yet has also produced some interesting findings relating to patients' reliance on health professionals as another component of their physical self care during treatment for cancer. However, the findings from this study also offered a different perspective of patients' self care, namely, those activities that patients carried out as part of their *emotional* self care. Interestingly, much existing research on self care in patients with cancer, such as those studies described earlier, has failed to investigate the emotional impact of undergoing treatment for cancer and how patients attempt to manage this. Instead, such research has tended to focus primarily on the physical impact of cancer and its treatments and its' subsequent management using quantitative designs (Dodd, 1988; Nail et al, 1991; Foltz et al, 1996; Richardson and Ream, 1997; Borthwick et al, 2001; Wong et al, 2006). Some of these studies have also focussed specifically on the impact and management of one or two specific treatment-related side effects, such as fatigue (Dodd, 1988; Richardson and Ream, 1997) and mucositis (Wong et al, 2006), rather than the self care strategies that people employ in managing the wider emotional and social impact of undergoing chemotherapy treatment for cancer.

In speaking of their emotional self care, the patients in this study spoke of activities that they carried out to manage their emotional responses towards being diagnosed with, and undergoing treatment for, cancer. These included, strategies employed to help them to make sense of their situation, to help them to maintain a sense of normality and identity, to help them learn what to expect from the treatment process and how the treatment typically affected them, and to help them not dwell on their situation. The diagnosis of cancer, as with chronic illnesses, can lead to a process which disrupts peoples' everyday lives and their sense of normality, identity and self confidence (Bury, 1982; Charmaz, 1983; Loveys and Klaich, 1991; Charmaz, 2002). Chronic illness may cause an ending to familiar life (Kralik and van Loon, 2007). People with chronic illness feel disrupted, frightened, and

anxious and become aware that they are not living up to social norms and their sense of self and identity is fragile or always shifting (Telford et al, 2006; Kralik and van Loon, 2007). Hence, it is unsurprising that the patients in this study carried out such activities in managing the emotional impact of being diagnosed with, and undergoing treatment for, cancer, and as in any chronic illness, people attempt to reconstruct a meaningful sense of self that fits with the changes that they have experienced in their lives (Bury, 1982).

Such activities, however, have rarely been focussed on in relation to self care in patients undergoing treatment for cancer, since as acknowledged earlier, existing work has primarily focussed on the physical impact of treatment and patients' management of this. Yet, within other bodies of literature such as coping more generally with cancer and chronic illnesses, there is widespread evidence of the use and importance of such activities in regulating peoples' emotional responses. 'Normalising' is a key strategy frequently used by patients diagnosed with chronic illness (for example, Small and Lamb, 1999; Koch et al, 2000; Kyngas et al, 2000; Mok and Tam, 2001; Taylor, 2001; Kralik, 2002; Loeb, 2006) and employed to help patients make sense of their situation and create order for their future management of it. Hence, the findings from the current study support existing findings and demonstrate the importance of this as a self care strategy for people undergoing chemotherapy treatment for cancer. In their qualitative study of men (n=6) diagnosed with diabetes, Koch et al (2000), identified that patients frequently spoke of 'normalising' their illness into their lives, for example, by making blood glucose testing an everyday activity of their normal routines and carrying on with the daily activities that they would have done regardless of having diabetes. Kralik's (2002) study also highlighted the importance of the use of 'normalising' strategies in her qualitative findings which demonstrated that women (n=81) diagnosed with chronic illness appeared to move through a complex trajectory involving both an 'extraordinary' phase, characterised by turmoil and distress, before moving on towards an 'ordinary' phase which involved incorporating the chronic illness into their lives. Similar to the patients in the current study, this 'ordinary' phase was

paramount for regaining a sense of self and for maintaining a sense of the future (Kralik, 2002). The quest for 'ordinariness' in Kralik's (2002) study also involved the process of learning and identifying the changes that were necessary so that illness could have a place in their lives.

Hence, similar to the patients in Kralik's (2002) study, this may have been part of the patients' attempts, in the current study, to move towards a degree of acceptance of their illness, to normalise the impact of their treatment as much as possible and to find a way of incorporating this into their daily lives and to live with the changes that it brought about. Similar findings from qualitative studies have been reported by Kyngas et al (2000) in their study of adolescents with cancer (n=14) in Finland and by Mok and Tam (2001) in their study of Chinese patients with chronic renal failure (n=11), emphasising the importance of this strategy in patients' attempts to successfully manage and cope with their illness and its impact. As noted in Kralik's (2002) study, these processes which involved learning what to expect, accepting the changes brought about by the illness and incorporating these into their normal lives may have helped the patients in the current study to achieve a sense of progress, not necessarily with the physical impact of their treatment, but emotionally in being able to reconstruct their sense of self and their usual roles within their family, for example, as a wife or husband and as a mother or father. The findings from the current study support this view since the qualitative analysis identified that several patients commented on the importance of learning how to incorporate the effects of their cancer and its treatments into their daily lives and the importance of being able to carry on with their normal roles within the family and being able to fulfil their normal responsibilities.

The importance of information seeking to prepare themselves for the lifestyle changes that they had to make and to offer reassurance and build their sense of confidence and independence has been identified in several qualitative studies (Koch et al, 1999; Kyngas et al, 2000; Kralik et al, 2004; Kralik et al, 2005). Seeking information was a strategy

reported in the current study and which appeared to be central to the theme of 'learning what to expect' in the current study. This theme also involved patients learning how their body worked, finding alternative ways to do something that was important to them, and identifying what their goals and limits were. These findings support those of Kralik et al's (2004) qualitative analysis in which nine people with arthritis spoke of their self management and identified the importance finding alternative ways to do the things that were important to them, staying realistic with regards to personal goal setting and recognising and admitting the boundaries of what they felt able to do.

Ultimately, the findings from the current study offer an understanding of how people undergoing chemotherapy treatment for cancer manage their emotional responses which is valuable since little work within this particular body of literature has so far focussed on this. The findings also make a valuable contribution to the evidence base since they offer support for a large body of work literature on the acceptance of, and transition in, chronic illness (and cancer) (Bury, 1982; Charmaz, 1983; Koch et al, 1999; Koch et al, 2000; Paterson, 2001; Thorne and Paterson, 2001; Charmaz, 2002; Kralik, 2002; Koch et al, 2004; Kralik et al, 2004, Woodgate, 2005; Kralik et al, 2005; Kralik et al, 2006; Bertero and Chamberlain Wilmoth, 2007). The findings from the current study reinforce the central themes of this work which demonstrate the process of transition that patients go through and the strategies that they undertake in order to help them reconstruct their sense of self, to help them prevent their illness from dominating their lives and to help them to create order and maintain a sense of normality following a diagnosis of illness. Hence, these findings reinforce the view that self care is more than just a process of 'doing' but is intertwined with their sense of identity (Kralik et al, 2004) as well as their sense of normality and hopes for the future.

In contrast to the earlier discussion, where patients' physical self care activities were seen to be akin to the 'medical model', their emotional self care activities and this so called process

of 'transition' could be likened to the 'social model' of health. The social model of health considers wider factors as influences of health and not just the absence or presence of disease and seeks to lessen medical dominance (Craddock and Reid, 1999). Patients' emotional self care may be seen to be akin to this model since they appeared to expect little professional assistance in managing their emotional responses to being diagnosed with, and undergoing treatment for, cancer. This is in stark contrast to their physical self care in which patients seemed to expect a high degree of advice, assistance, reassurance and supervision from health professionals in managing the physical impact of their treatment (as evidenced by the emergent theme of 'relying on health professionals').

There are several explanations for this. Firstly, unlike physical self care, which patients frequently spoke of as being the domain of health professionals and something that, where possible, they could contribute towards, emotional self care may have been seen as something that was intrinsic to the person themselves and how they typically coped or regulated their emotions in daily life. In other words, these were strategies that were part of peoples' social make up and integral to their sense of self and identity and were simply how they typically dealt with such disruptions to what was considered their normal lives. Secondly, it could be that health professionals' interactions with patients and guidance at this time may primarily guided towards focussing on physical symptoms and their management, hence prioritising the disease over the patients' life, as also demonstrated in a recent study of the interactions between nurse and patients with diabetes (Zoffman and Kirkebold, 2005). Hence, this is may have led patients to view health professionals as the 'experts' in managing physical symptoms. Thirdly, managing the physical impact of patients' treatment was something that placed high demands on people in terms of learning how to identify symptoms, judge their severity and respond appropriately and effectively to these. In essence, undergoing treatment meant that patients were encountering physical changes that they had never previously had to deal with and hence, may not have known how to deal with these effectively and, therefore, perceived themselves to be less

experienced in managing these. Managing emotions, on the other hand, may not have been seen as “new” but rather people may have learned and developed particular styles of managing their emotions over the course of their lifetime, and hence, this may have been seen as less of a challenge in comparison with their physical self care.

The importance of these findings and in particular, the ways in which patients managed both their physical and emotional wellbeing have relevance to, and implications for, nursing practice, theories relating to self care and future research. In particular, the distinction between patients’ physical and emotional self care is important because this understanding seems to be missing from many existing theories driving self care research, for example, Orem’s Model of Self Care. Orem’s Self Care Model, being a model to guide nursing practice, fails to describe how patients become involved in self care and rather focuses on the role of the nurse in patients’ self care. The Conceptual Symptom Management Model developed by Dodd et al (2001), also views self care in terms of symptom management, yet is unclear as to whether they mean simply physical symptoms or emotional symptoms too. This knowledge, therefore, is important to the theoretical underpinnings of self care and for adding to the evidence base on the range of physical, and particularly, emotional self care activities that are commonly carried out by patients undergoing treatment for cancer. It is also clinically important for helping to inform practitioners about the kinds of self care activities people with cancer carry out and how they can help to support patients in their pursuit of carrying out such activities. The importance of this was highlighted by Zoffman and Kirkebold (2005) who identified that when nurses tried to address patients’ management of the effects of diabetes without having specific knowledge of patients’ experiences of living with diabetes and their priorities, patients were more likely to show reluctance towards these actions and become despondent with health professionals. The theoretical and clinical implications of the study findings are further considered in sections 12.6, 12.7, and 12.8.

The following section considers the findings on the association between patients' perceptions of control and their attitudes towards self care, the importance of these and their relevance to existing research, particularly the research considered in Chapter 4, and the wider literature. The implications of these findings for theories relating to self care, clinical nursing practice and future research are then discussed in sections 12.6, 12.7 and 12.8.

12.5 Perceptions of Control

12.5.1 Conceptualising Perceived Control

The qualitative interviews revealed that when asked about their perceptions of control, patients spoke of control as being the degree to which they perceived that they could influence their experience of the physical and emotional effects of their treatment and the importance of being able to do this. These findings, like in the earlier discussion on the meaning of self care, make a valuable contribution to the knowledge base since they help to clarify the concept of control from the patient's perspective, rather than from the perspective of academics and other professionals. This is relevant because, as highlighted in Chapter 4, there are many different conceptualisations and types of control which have been proposed by academics and professionals and this has contributed towards a lack of theoretical clarity in this area of research (Skinner, 1996; Wegner, 2002). For example, people may perceive that they have control over the course of the illness itself rather than control over the effects of the illness and its treatments, or vice versa (Thompson et al, 1993; Newsom et al, 1996). This lack of clarity has contributed to the difficulties that researchers experience in deciding which conceptualisations and types of control are most relevant to the focus of their research and how to appropriately measure these (Skinner, 1996; Wegner, 2002). Furthermore, it is not known to what extent these existing conceptualisations have attempted to understand 'control' from the patients' perspective ,therefore, it is difficult to determine whether they really capture all that control means to patients. The relevance of these dilemmas was highlighted in the findings from this study by the different ways that control was conceptualised in the qualitative interviews and the

quantitative questionnaire used to measure control, namely the Illness Perceptions Questionnaire (revised) (IPQ-R) (Moss Morris et al, 2002). In particular, whereas in the qualitative interviews, patients spoke of control as being the degree to which they perceived they had influence over the impact of their treatment, the components of the IPQ-R measured control in relation to management of the illness itself rather than patients' control over the effects of the treatment. This is important because it shows the different conceptualisations of control that were used in both the qualitative and quantitative components and questions whether these issues may have contributed to the nature of the findings that were produced by both approaches on the relationship between control and self care. For example, had the qualitative component used the conceptualisation of '*control over the cancer*' itself, rather than over the '*impact of treatment*', the findings may not have identified a relationship between control and perceptions towards being involved in self care. In this scenario, patients may have perceived that they had little influence over the progression of the cancer itself and, therefore, perceived their involvement in self care differently. On the other hand, had the quantitative component used the conceptualisation of '*control over the impact of treatment*' rather than the cancer itself, or had used a different combination of instruments with which to measure control, the findings may have demonstrated a relationship between control and the degree of self care that patients carried out. Hence, the qualitative interviews were key for allowing patients to identify their own meanings of the term 'control' and for considering how this related to the quantitative measure.

12.5.2 Influence on Self Care

In speaking of their perceived degree of control over managing the impact of their treatment, the qualitative interviews showed that some patients held high perceptions of control whilst others held lower perceptions of control. From these differences, the qualitative interviews demonstrated that patients who perceived themselves to have a higher degree of control during their treatment spoke differently about their attitudes towards their

active involvement in self care from those patients who perceived themselves to have a lower degree of control during their treatment. In particular, patients who perceived a high degree control spoke of being able to limit the impact of their treatment through their own actions, that being actively involved in their self care was important and were interested in taking on this role, and that they would use a greater range of self care strategies in helping to manage the impact of their treatment. Conversely, patients who perceived a lower degree of control spoke of having little influence over the impact of their treatment, that their active involvement in self care was less important and were less likely to expect to take on an active role, preferring to leave the management of treatment-related effects to health professionals, whom they regarded as the “experts”.

These findings are interesting because they support previous claims made within the existing literature around the characteristics of people who regard themselves as having a high or low degree of control. In particular, the study findings concur with the belief that people with a high degree of control are more likely to believe that they can influence their situation, are more interested in problem solving and more likely to act in ways to help them regain control, and exert more effort and perseverance with the activities that they carry out (Skinner, 1995; 1996; Ajzen, 2002). They also concur with the belief that people with a lower degree of control are likely to believe the opposite; that they perceive themselves as having little influence over their situation and tend to avoid challenging situations and opportunities to regain some degree of control (Skinner, 1995; 1996).

Although there is little research which has investigated the influence of control on involvement in self care amongst patients with cancer, there are some studies (some of which were considered in Chapter 4) which can be used to illustrate the links between control and proactive self care or health promoting behaviours. In particular, Taylor’s (1983) report of her early qualitative work highlighted that higher perceptions of control were most often associated with positive health-related behaviours, such as carrying out self

care, making dietary changes and medication and imagery. In another study using a quantitative design, Henderson and Donatelle (2003) found that higher reports of control were associated with a greater use of complementary therapies in a quantitative study of 551 women with breast cancer in America. Finally, a phenomenological study with 12 patients with haematological cancers, Bulsara et al (2003) identified four themes (strategies) that were used by patients who had a strong sense of empowerment and control over coping with the impact caused by their condition. The main themes identified were having a fighting spirit, attempting to maintain a reasonable quality of life, changing life's priorities and maintaining hope and a positive attitude. In other studies focussing on patients' information seeking behaviour, patients with greater perceptions of internal control were more likely to seek written medical information (Koo et al, 2002, 2006). The findings from these studies appear to support the view that patients with higher perceptions of control or perceptions of internal control are more likely to perceive that they can influence their situation through their own actions and are more likely to view an active role in self care as important and strive to achieve this role.

The qualitative interviews also highlighted that perceptions of control had an influence, not only, over the importance with which people viewed their active involvement in self care and the likelihood that they would take on this role, but also the range and nature of self care strategies that people used to manage the impact of their treatment. Rather interestingly, and perhaps most importantly in terms of its implications for clinical nursing practice, is the finding that patients who perceived themselves to have a lower degree of control spoke of using one or two self care strategies compared to those who perceived a higher degree of control and who spoke of a far wider range of self care strategies that they used to manage the physical impact of their treatment. Principally these strategies involved relying on health professionals and using medications. Similar findings were identified by Link et al (2004) who, in a study of patients with cancer (n=44), compared preferences for taking control and how this influenced their use of strategies designed to manage the impact

of their diagnosis. Link et al's (2004) findings demonstrated that patients who were more likely to try and exert a degree of control following their diagnosis reported a greater use of proactive strategies, such as, making dietary changes and exercising, compared to a greater use of reactive strategies such as not dwelling and avoiding cancer information in patients who did not wish to exert a degree of control. Such findings hold relevance to those from the current study since, relying on health professionals and using medications may be considered reactive strategies since they do not demand that patients adopt a more active role in their involvement in self care. Subsequently, the findings from the current study support Link et al's (2004) in demonstrating the relationship between patients' perceptions of control and their attitudes towards being actively involved in managing the impact of cancer and its ensuing treatments. Not only this, but the findings from the current study confirm support for the relationship between control and behaviour as conceptualised in Leventhal's Self Regulation Model. Further discussion of this and the implications of the findings for Leventhal's Self Regulation Model are considered in section 12.7.

Some possible explanations for the reliance of 'reactive' strategies amongst patients who perceived themselves to have a low degree of control can be found in the qualitative data. In particular, as described in Chapter 9, these patients perceived that they were ill prepared for undergoing treatment, did not fully know what to expect from the treatment process and how this would impact on them, and how to manage this impact. They often perceived, therefore, that health professionals were in the position of 'experts' and that it was they who were in control of managing the impact of treatment, rather than themselves whom they considered to be less experienced in managing the impact of treatment and fearful of experimenting with their self care and "getting something wrong" or "making things worse". They also doubted the efficacy of their own self care efforts and struggled to determine whether the physical effects that they were experiencing were a result of the treatment or something else, for example, co-morbidities or the cancer itself recurring. Subsequently, they believed that there was very little that they could do to prevent or

control the impact of their treatment and the nature and severity of the various side effects that they may experience and that this was simply part of the treatment process that they had to endure.

These findings are valuable for offering a greater insight into the influence of control on self care behaviour than has previously been identified. In particular, the findings offer an insight into the factors that influence the degree of control that patients perceive themselves to have during treatment and how these perceptions influence their perceived willingness and capabilities to take on a greater responsibility for their self care. These findings also help to explain the factors involved in influencing patients' preferred role in self care and also their self care decision making in terms of the nature and range of self care activities that they are likely to employ during their course of treatment. Such findings have implications for clinicians because they demonstrate the importance of peoples' perceptions of control in influencing their perceived ability to take a greater responsibility for their self care and highlight the areas in which these patients may need a greater level of support to do this. Further clinical implications of these findings are considered further in the following section. The relevance of the findings to Leventhal's Self Regulation Model are considered in section 12.7 and their implications for informing future research are discussed in section 12.8.

12.6 Implications for Clinical Practice

The findings from this study are valuable for emphasising the importance of the patient's experience and the patient's perspective and how this approach can contribute to a fuller and more accurate understanding of what self care and control means to people, how people become involved in their self care, and the factors that influence their preferred level of involvement in self care. The importance of acknowledging and embedding the patients' experience within health policy and healthcare delivery in making services more responsive to patients' needs, more acceptable and equitable, and to improve quality and outcomes of

care is now becoming well recognised (Department of Health, 2003; Hubbard et al, 2005; Ryan et al, 2005; Worth et al, 2005; Scottish Government, 2007). Listening to the patient's experience is of particular clinical importance for nurses since they have been heralded in recent healthcare policy (Scottish Executive, 2006) as champions of the patients' experience and are commonly considered to have caring attributes such as approachability, empathy, kindness and an ability to listen respectfully to the person, which is at the heart of their daily practice (Kralik et al, 1997; Fealy, 2004; Wilkin and Slevin, 2004). Hence, nurses in particular are seen to be in a prime position to encourage and support patients' involvement in their self care in accordance with patients' perceptions, attitudes and preferences for involvement in self care.

The findings from this study are valuable for revealing how the patients in this study became involved in their self care during their treatment and all that this entailed in terms of both their physical and emotional self care. Understanding both the physical and emotional components of patients' self care and exactly what these comprise are clinically important for several reasons. Firstly, it offers nurses a greater understanding of what people do as part of their self care, both in terms of highlighting its' physical and emotional components as well as the specific activities that people carried out within these domains. Secondly, it reinforces the importance of nurses focussing on the self care of the person, as opposed to the self care of the physical effects of the cancer and its' treatments. This is particularly significant given the importance of providing holistic nursing care (Department of Health, 2000; Royal College of Nursing, 2003; Nursing and Midwifery Council, 2004; Scottish Executive, 2005b). Thirdly, it emphasises that because self care is not simply about treating the effects of the disease or its' treatments but rather, is wider than this, supporting involvement in self care will naturally involve accessing resources and contacts that are outwith the traditional boundaries of the nursing role and indeed, the health service. Such implications draw attention to the importance of nurses being aware of and being able to direct patients towards, existing and alternative self care support services that are available

from other agencies and the role of the voluntary sector (Department of Health, 2006b). The need for new joined up ways of working which cut across traditional boundaries have been strongly emphasised within health policy across the UK, in the recently published *Supporting People with Long Term Conditions* (Department of Health, 2005a), and its' complementary document, *Supporting People with Long Term Conditions to Self Care* (Department of Health, 2006b) and in Scotland, *Delivering for Health* (Scottish Executive, 2006) and *Better Health, Better Care* (Scottish Government, 2007).

Understanding patients' perceptions of control during treatment and how these influence their likely involvement in self care and their self care decision making have important implications for nurses. In particular, the findings from this study suggest that patients' perceptions of control were indicative of whether they wished and expected to assume a more or less active role in their self care. This raises several important issues for nurses. Firstly, it highlights the importance of understanding control from the patients' perspective since how can nurses attempt to enhance their patients' perceptions of control if there is little understanding as to what this means to patients. Secondly, it draws attention to the importance of carrying out individualised assessment of patients' preferences for control and their current and desired levels of control given that these are so inextricably linked to their perceptions of self care. Finally, it highlights the importance of nurses' practice being directed towards strategies which will help to enhance their patients' perceptions of control and address those issues that may prevent patients from exerting a degree of control over their self care (Bulsara et al, 2004).

Since patients' perceptions of control were found to be inextricably linked to their perceptions of their self care, it is perhaps unsurprising that those patients who perceived a lower degree of control over their self care, were those patients who showed the greatest reliance on health professionals as a self care strategy. This is worthy of particular note as it has several implications for clinical nursing practice. Firstly, it suggests that undergoing

treatment for cancer and the management of its ensuing effects remain a daunting and challenging prospect for some patients and one in which they can often feel ill prepared for. This draws attention to the importance of adequately informing and preparing patients for what to expect at the beginning but also during the course of patients' treatment since this may help to enhance their perceptions of control and the likelihood that they will feel capable of, and interested in, becoming actively involved in their self care. Secondly, it makes us mindful of the fact that all patients are different and that their preferences for a lesser or greater degree of responsibility for, and involvement in, their self care are likely to vary, as recently acknowledged in *Supporting People with Long Term Conditions to Self Care* (Department of Health, 2006b). As such, the importance of matching the patients' need with a more effective response has been emphasised within health policy (Scottish Executive, 2005b). What all of these issues highlight, however, is the importance of regular and timely assessment of patients' self care needs and preferences, good communication between patients and nurses, tailored and individualised supportive care and information provision, and the creation of a supportive culture in which self care is actively encouraged but yet viewed as a continuum where support from nurses can be provided and tailored towards patients at all stages of this continuum.

Finally, the idea of supported self care and nurses' role within that is becoming a major priority for healthcare across the UK (Department of Health, 2005a; Department of Health, 2006b; Scottish Executive, 2005b; Scottish Executive, 2006; Scottish Government, 2007). Hence, the findings are not only valuable for informing nurses' individual practices but, on a wider scale, are important for informing the development of supportive self care interventions. The discussion in Chapter 3 critiqued some existing supportive self care interventions for patients with cancer and drew particular attention to their failure to understand the patients' perspective of, and priorities for, self care as well as their individual beliefs and perceptions and how these influence their involvement in self care. What the findings from this study do, is draw attention to the importance of these issues and

subsequently, they can be used to contribute towards the development of patient centred, supportive self care interventions. In particular, the findings from this study show that promoting involvement in self care, and thus the development of supportive self care interventions, is not simply a case of employing traditional self care approaches such as information giving and education. Rather, as acknowledged in *Supporting People with Long Term Conditions to Self Care* (Department of Health, 2006b), it is about providing a range of options to people in helping them to self care in the way that they wish to and should incorporate approaches which encourage nurses and patients to work together to identify issues central to their own self care, encourage problem solving, sharing of tailored and relevant information, and approaches which enhance peoples' perceptions of control over managing the effects of illness and its treatments.

Hence, the findings from this study can be seen to hold relevance to nurses' clinical practice. The following section now considers the implications and relevance of the study findings for theories on self care and in particular Leventhal's Self Regulation Model which was adopted as the theoretical framework in this study.

12.7 Implications for Theories Relevant to Self Care

There are several aspects of the study findings which hold relevance towards existing theories of self care and to Leventhal's Self Regulation Model (SRM). In particular, the following discussion considers the importance of the patients' perspective and the extent to which this has been embedded within existing theories, the importance of the distinction between patients' physical and emotional self care and the degree to which this has been described and acknowledged within existing theories, and the role of control in self care and the extent to which this has been recognised as a factor influencing patients' perceptions towards, and involvement in, self care within existing theories.

The study findings emphasised the importance of the patients' perspective in understanding what self care means to people how they perceive their active involvement in their self care. Hence, to be of clinical utility and to inform future research, theories relating to self care should be driven from the patients' perspective. In Chapter 3, Orem's self care model was criticised for being a model primarily devised in order to guide nursing care, rather than to specifically understand the process of self care from the patients' perspective. Thus, the findings from this study seem to be at odds with the focus of Orem's Self Care Model and the focus on the patients' perspective within this model is questionable. The Conceptual Symptom Management Model (CSMM), developed by Marilyn Dodd and colleagues, however, does attempt to understand symptom experiences and symptom management strategies from the patients' perspective. This model, however, is still being developed and refined, yet, the findings from this study offer support for the patient-centred approach which is the focus of the model. Similarly, Leventhal's' Self Regulation Model (SRM) is driven by a patient focus since it sets out to understand how people make sense of, and respond to, the effects of illness and its treatments.

Secondly, the study findings demonstrated the distinction between the self care activities that patients carried out to manage the physical impact of undergoing treatment and those activities that they carried out in managing their emotional response to this. This is important as it describes more about the nature of patients' self care and subsequently, is of importance to theories which seek to understand, describe and explain patients' involvement in self care. Orem's SCM does little to suggest that self care has been considered in both physical and emotional terms, meaning that in light of these study findings, its application to patients with cancer may be limited. The CSMM appears to focus on "symptoms" that are reported by patients, yet it is not known what the nature of these symptoms are. Hence, it is not clear whether the CSMM captures both patients' strategies for managing both their physical and emotional wellbeing. As noted in Chapter 3, the CSMM is still in its infancy and at the stage of requiring refinement of the concepts

and a richer description of how it applies to patients with cancer. The findings from this study could, therefore, contribute towards the development of this model by providing contextual information on self care in patients undergoing treatment for cancer and emphasising the importance of including an emotional self care component within the model. This would seem important since the model was originally developed out of a need to develop a consistent and effective approach to symptom management in promoting patients' involvement in self care (Dodd et al, 2001).

Leventhal's SRM, on the other hand, focuses on the ways in which individuals direct and monitor their activities as well as their emotions in order to achieve their goals (Cameron and Leventhal, 2003). As shown in the diagram of the SRM in Chapter 3, peoples' emotional responses appear to operate in parallel with their beliefs about the particular threat to their health or wellbeing. Ultimately the model shows similarities with the findings from this study which discussed the ways in which people spoke about their self care as having both physical and emotional components and adds to the existing body of work which supports the components of Leventhal's SRM and their influence on behaviour (for example, Ziff et al, 1995; Petrie et al, 1996; Griva et al, 2000; Cohen, 2002; Horne and Weinman, 2002; Drossaert et al, 2003; and, Whitmarsh et al, 2003). However, a neglected area in both the empirical literature and in the SRM itself is the contribution of coping with emotions (Moss Morris, 2005). The qualitative component of this study, therefore, was also particularly valuable for understanding more about the ways in which patients undergoing treatment for cancer respond emotionally in managing the impact of undergoing treatment. Consequently, these findings make a valuable contribution to the evidence base given that less is known about the SRM and the contribution of coping with emotions (Moss Morris, 2005).

Finally, the study findings draw particular attention to the role of control and the influence of this on patients' perceptions towards their self care and the nature of self care activities

that they employ during treatment for cancer. This demonstrates the importance of the inclusion of concepts such as, control in theoretical models relating to self care. Again, it is unclear in Orem's SCM whether there has been much consideration of control as a factor influencing patients' self care and, therefore, questions its clinical utility in light of the clinical implications that these findings have for guiding nurses towards strategies which help their patients to gain control and facilitate their involvement in self care. The CSMM does allude to 'person' factors as having an influence on self care in which demographic factors, psychological factors, sociological factors, and physiological and developmental factors which are all believed to influence a person's self care. However, it is not known to what extent the issue of control has been focussed on as an influencing factor on self care within this broad umbrella term and subsequently, its role within the model. Consequently, it is, at present, unclear how the model would be used to understand patients' perceptions of control and the influence of these and how it would be used to inform nurses' practice on how they can enhance their patients' perceptions of control and thus, facilitate their involvement in self care.

The issue of control is a key construct within Leventhal's SRM and was another reason why it was this model that was chosen as the theoretical framework for the study. Although the quantitative findings from this study demonstrated no relationship between control and the number of self care activities carried out (exploratory hypothesis 1), the qualitative findings revealed that patients' perceptions of control were related to the nature and range of self care strategies that people carried out. Therefore, the qualitative findings from this study helped to contribute towards a greater understanding of the relationship between control and self care behaviour. In particular, the qualitative interviews were useful for exploring some of the possible factors that influenced patients' perceptions of control and, therefore, subsequently, influenced their attitudes towards their self care behaviour. In essence, the inclusion of the qualitative component helped to reveal, not just the presence of a relationship between control and self care but was also able to contextualise this

relationship through the lived experience of the patients in this study. This is important since the SRM is traditionally a model of coping yet the findings from this study demonstrate support for the model in terms of the influence of control on self care behaviour.

Having considered the relevance and implications of the study findings for existing theories relevant to self care and in particular, Leventhal's SRM, the following section considers the implications of the study findings for informing future research.

12.8 Implications for Future Research

This study has several implications for future research both because of its principal findings and because it has demonstrated the value of adopting a mixed method design in researching patients' involvement in self care yet has also demonstrated some of the potential challenges associated with this approach. In terms of its main findings, the study has principally demonstrated the importance of understanding the patients' perspective of self care and control and has identified the distinction between patients' physical and emotional self care and how patients' perceptions of control influence their attitudes towards their subsequent involvement in their self care. These findings have implications for future research given that previous research on interventions to support peoples' involvement in self care has, to date, adopted a patient perspective and as such acknowledge the variability in patients' self care responses and preferences (as demonstrated in Chapters 3 and 5) (Kendall and Rodgers, 2007). Hence, further work is needed to not only further understand the impact of illness and self care responses from the patients' perspective (Kennedy et al, 2007) but also to ensure that future research on interventions to promote peoples' involvement in self care allows for the patients' perspective to be at the focus of the investigation, allowing for such perceptions and variability in response to be incorporated within the intervention itself.

This is particularly important in light of the distinction made in this study between patients' physical and emotional self care. This finding demonstrates the importance of the patient's perspective and the reaffirms the importance of acknowledging that each individual experiences their illness in a different way and naturally they also self care in different ways too. It is important that this understanding is incorporated into the future development of interventions since this will help to ensure that interventions are tailored and, therefore, more likely to match patients' self care needs and preferences. These findings also call for future research to conceptualise self care as having these very distinct components in an attempt to accurately describe and explain patients' involvement in self care. The emotional self care that patients carry out is particularly relevant in light of the literature on transition to chronic illness and is important for understanding how patients with cancer make sense of their situation and attempt to normalise it and create order for the future. It is acknowledged by the researcher, however, that the findings from this study relate to a very specific patient group, namely, patients undergoing one type of chemotherapy treatment for colorectal cancer. Therefore, it would be valuable for future research to further investigate the nature of patients' involvement in self care and all that this comprises in patients with different tumour types, patients receiving different treatment types and patients at different stages in the cancer trajectory, for example, longer term survivors of cancer.

Given the moves towards encouraging a greater degree of involvement in self care within health care policy and the literature, there is a greater need to understand the factors that influence whether someone does or does not become involved in their self care. Whilst there is some literature on the role of patients' symptom experiences in relation to their self care (Stoller et al, 1993; Richardson and Ream, 1997; Rhodes et al, 1998; O'Neil and Morrow, 2001; Borthwick et al, 2003), the literature is vague and inconclusive on the influence of demographic, social and psychological factors on patients' subsequent involvement in self care. This study made an attempt to understand more about how patients' perceptions of control influence their involvement in self care. Although the

findings demonstrated that there was no statistically significant relationship between control and the degree of self care carried out by patients, there was a relationship between patients' perceptions of control and their attitudes towards their likely active involvement in self care and the importance with which they viewed this role. This is important for informing future research for two reasons. Firstly, they identify the importance of patients' perceptions of control and, therefore, call for future research to explore this relationship further and in particular to identify more about the factors that influence patients' perceptions of control, as was uncovered in the qualitative analysis in this study. These findings are particularly valuable for informing the future development and testing of supportive self care interventions for patients with cancer, since existing programmes (discussed in Chapter 3), for example, *the Expert Patient Programme* in the UK has had modest improvements only in promoting involvement in self care (Kennedy et al, 2007). Kennedy et al (2007) claim that this maybe because such programmes focus on teaching self care skills, and this alone is unlikely to be sufficient for effective self care. Thus, the findings from this study, demonstrating the relationship between control and attitudes towards involvement in self care, have implications for the future development of such interventions since they highlight the importance that patients' beliefs and perceptions play in influencing their attitudes towards their subsequent involvement in self care.

In terms of methodology, the choice of design, its implementation and the challenges involved (as discussed in section 12.3) in raise several issues for future research. Firstly, the findings demonstrated the value of using the mixed method approach for understanding patients' involvement in self care and the influence of factors, such as their perceptions of control, on their subsequent involvement in self care. The patient perspective within this methodology was particularly important for informing future research since it identified the mismatch between the conceptualisations of self care and control in both the qualitative and quantitative data sets. This has implications for future research since it shows the importance of researchers understanding exactly what it is that they intend to measure

within their study and shows the impact of this on the nature of the study findings that are produced. In addition to this, the patient perspective obtained through the qualitative approach, helped to identify that the instruments used in this study failed to adequately capture patients perceptions, and involvement in, self care and their perceptions of control in its entirety. Not only does this have implications for the conceptualisations of self care and control used in future research but it highlights the challenges associated with the use of existing instruments. Subsequently, it is important that future researchers are aware of such issues and how this can influence their findings and calls for revised instruments which conceptualise self care and control from the patients' perspective and which reflect the multidimensionality of patients' perceptions and experiences.

The methodology used in this study highlighted the inadequacy of using a single approach alone to understand patients' involvement in self care. For example, had simply a quantitative approach been used alone, it would have revealed no relationship between control and self care, whereas the qualitative approach identified a relationship between control and patients' attitudes towards their involvement in self care. The implications of this are important for informing future research designs since existing research has primarily relied on the use of quantitative designs (as discussed in Chapter 3), and, therefore, has led to a lack of understanding of how patients perceive self care, how they become involved in self care and why, and the factors that influence their subsequent involvement. Furthermore, although the value of researching patients' involvement in self care using a mixed method approach in this study was demonstrated by way of their complementary findings, there is still much to be known about how qualitative and quantitative data sets can be meaningfully combined in contributing towards a greater understanding prompting future research to explore these issues.

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APPENDICES

Appendix 1 Patient Information Sheet

PATIENT INFORMATION SHEET How your control and confidence affects your self-care during chemotherapy treatment



UNIVERSITY OF
STIRLING

DEPARTMENT OF
NURSING AND MIDWIFERY

Invitation

You are being invited to take part in a research study. Before you decide, it is important that you understand why the research is being carried out and what your taking part in it would involve. Please take the time to read the following information carefully and discuss it with others if you wish, such as your friends and family. If there is anything that you are not clear about or would like further information on, then please speak to Lisa Kidd, who is a nurse and is the main researcher for the project and ask any questions that you have. Please do not feel pressured into making a quick decision - take the time to decide whether or not you wish to take part.

Thank you for reading this

What is the purpose of the study?

Chemotherapy treatment may cause some side effects which you may experience while you are at home. The things that you do to prevent, control or relieve side effects at home during your treatment are known as 'self care activities' by doctors and nurses. This can include, for example, taking your anti-sickness medication to prevent and relieve sickness, drinking plenty fluids if you've been having diarrhoea, or resting when you feel you need to. **'Self care' refers to any activity that you can do yourself to prevent side effects from occurring or to help make your side effects better.** Many people carry on with their usual routines during treatment however, there are some people who don't always feel well enough to do this.

This study is being carried out as the basis of an educational degree (Doctor of Philosophy) and plans to look at how your confidence changes and if this affects how you look after yourself during your chemotherapy treatment.

Why have I been chosen?

You have been chosen because you are about to start chemotherapy treatment for bowel cancer (colorectal cancer).

Do I have to take part?

It is up to you whether or not you would like to take part. You will be given this information sheet and if you **do** decide to take part, you will be asked to sign a consent form (you will be given a copy of this to keep).

If you decide **not to take part** or you change your mind and wish to **withdraw** at any time during the study (even if the project has started), you do not need to give a reason and your treatment or care will not be affected in any way.

What does it involve?

The study involves thinking about the things that you do to help prevent, control or relieve your side effects and how confident you feel in being able to deal with your side effects. You will be asked to fill out a questionnaire booklet, a self-care diary

and may be invited to take part in an interview with the researcher about your treatment experiences. The study will not stop you from carrying out your usual activities or affect the treatment or any other medications that you are receiving. It is not expected that the study will involve any expenses for you.

What do I have to do?

Questionnaires

You will be asked to fill out a questionnaire booklet (containing 2 short questionnaires) asking about your confidence levels and how you feel about your illness and having treatment 3 times during your treatment (**on the first day of your treatment during your 1st, 3rd and 6th chemotherapy**). The questionnaire booklet will take you about 5 minutes to complete.

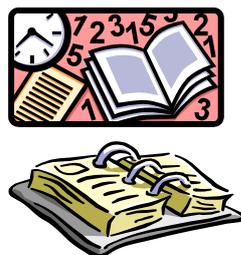
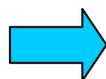
Diary

You will also be asked to fill out a short diary **following** these same 3 treatments (1st cycle, 3rd cycle, and 6th cycle). For each of these treatments, you will be asked to fill out the diary everyday (from the first day that you receive your treatment until the day that you receive your next treatment – this will be 14 days for patients having treatment every two weeks and 30 days for patients having treatment every 4 weeks). You can then return it to Lisa in the stamped addressed envelope provided. In the diary, you will be given a list of possible side effects and asked to tick all of the side effects that you have experienced and how bad they were. You will also be asked if you did anything to help with these side effects and from a list provided, to tick what those activities were. The diary will take about 2-3 minutes to complete each day.

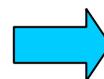
The pictures below explain what you will be asked to do during your 1st, 3rd and 6th chemotherapy cycles.



Complete the questionnaire booklet on the first day that you receive your treatment



Complete your self-care diary every day at home from the **first** day of your treatment until the **day before** you're due to have your next treatment.



Then post your diary back to Lisa

Interviews

You may also be invited to take part in an interview on 2 occasions. If you agree to take part in the interviews, the first of these will be at the **beginning** of your chemotherapy treatment and will ask you to chat about what you expect your treatment to be like and how confident you feel in being able to look after yourself. The second interview will take place once you have **finished** your treatment and will ask you about how you felt during your treatment, if you felt confident in looking

after yourself and what you did or did not do to take care of yourself during your treatment. You will also be able to chat about other issues that you feel are important during these interviews. With your permission, these interviews will be tape-recorded but these tapes will be destroyed once the research is finished.

What are the side effects to taking part in the research?

As you would be asked to focus a bit more on the side effects that you are experiencing, you may find this distressing. If you did feel anxious or depressed because of this at any time during the study, you could be referred to a nurse specialist or clinical psychologist who could help with how you are been feeling.

What are the possible benefits to taking part?

By using the diary, you will be able to keep a record of any side effects that you have experienced and what you have done to help with them. This may be quite helpful for letting you express your feelings and for remembering the things that you did to help with your side effects. For example, if you experience a similar side effect again, you can look back at what you did and how well it worked in making the side effect better. It may also help you to remember things that you want to talk about with the doctors and nurses when you return for treatment. The results from this project may also help others who are starting similar treatments.

What happens when the project stops?

Because taking part (or not) in this study does not affect the type or standard of treatment and care that you will receive, there will be no change to your treatment and care when the project stops.

Will my taking part be kept confidential?

If you agree to take part in the study, all information that is collected about you or from you will be kept confidential. Your details will not appear on anything other than the consent form and registration sheet, which will only be available to the researcher for the purpose of contacting you if necessary. Interviews will be tape-recorded to allow the researcher to accurately write about the discussion. All tapes and documentation relating to the study will only be identifiable to the researcher and will be safely and securely stored and then destroyed once the study is finished.

Your medical notes will be looked at by the researcher, only to collect some information about your diagnosis, chemotherapy, age, postcode and gender. Your General Practitioner (GP) will be sent a letter telling him/her that you are taking part in the study.

What will happen to the results of the project?

The results from the study will be used to help explain how your confidence affects how you look after yourself during chemotherapy treatment. Some of these results may be published in the researcher's PhD thesis, reports or journal articles, or presented at conferences by the researcher. When the study is finished you will receive a summary report of the study results. You will not be identified in any reports, publications or presentations about the study.

What if something goes wrong?

It is unlikely that anything you are asked to do during the study will cause you any harm but if you wish to complain, or have any concerns about any the way you have been approached or treated during the study, indemnity or compensation will be provided by the University of Stirling.

Who is organising the research?

This study is being conducted as part of an educational degree and is being organised by Lisa Kidd, the researcher who is a nurse working with the Cancer Care Research Centre, University of Stirling. The study also involves working closely with the doctors and nurses who are looking after you.

Who has reviewed this study?

The West Glasgow Ethics Committee has reviewed and approved this study.

Contact for further information:

If you have any questions or wish further information about the study, please contact:

Mrs Lisa Kidd
Research Student
Cancer Care Research Centre
Department of Nursing & Midwifery
University of Stirling
FK9 4LA

Telephone: 01786 84 9260
Email: lisa.kidd@stir.ac.uk

Thank you for taking the time to read this information sheet

Appendix 2 Consent Form

CONSENT FORM

How your control and confidence affects your self-care during chemotherapy treatment



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Patient Identification Number:

1. I confirm that I have read and understand the patient information sheet for this study and that I have been offered the opportunity to ask any further questions

2. I understand that my participation is voluntary and that I am free to withdraw at any time without my care, treatment or legal rights being affected

3. I understand that my medical notes will be looked at by the researcher from the University of Stirling or from regulatory authorities where it is relevant to my taking part in this research, and that any interviews will be tape-recorded and I give my permission for this

4. I agree to my GP being notified by letter of my participation in this research

5. I agree to take part in this research

Name of patient Date Signature

Researcher Date Signature

1 copy for patient's notes; 1 copy for researcher; 1 copy for patient

Appendix 3 Questionnaire Booklet

QUESTIONNAIRE BOOKLET
How your control and confidence affects your self-care during chemotherapy treatment



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This booklet contains two questionnaires that we would like you to fill in:

- 1) A questionnaire called '***the Strategies Used by Patients to Promote Health***' (***SUPPH***), which asks you about how confident you are feeling at the moment; and
- 2) A questionnaire called '***the Illness Perception Questionnaire (revised)***' (***IPQ-R***), which asks you some questions relating to the ideas and beliefs that you might have about your illness and treatment.

| | |
|---------------------------|--|
| Project Number | |
| Chemotherapy Cycle Number | |

Instructions for completing the questionnaire booklet

When to fill out this questionnaire booklet

You will be asked to fill in these questionnaires on the **day that you start** your 1st, 3rd and 6th treatment cycles. You can fill them out at any point during the day.

How to fill out the questionnaire booklet

Each questionnaire is clearly marked in the booklet. Both questionnaires will take you about 5 minutes to complete. Please take your time and try to answer **all** questions. All questions ask you to tick a box that you feel best relates to your answer for each question. There are no right or wrong answers to the questions and your answers will be confidential.

How to return the questionnaire booklet

Once you have answered all of the questions, please put this booklet into the stamped addressed envelope and return it to Lisa Kidd.

If you have any problems answering any of the questions, then please contact:

Mrs Lisa Kidd
Research Student
Cancer Care Research Centre
Department of Nursing & Midwifery
University of Stirling
FK9 4LA

Telephone: 01786 84 9260
Email: lisa.kidd@stir.ac.uk

Questionnaire 1
The Strategies Used by Patients to Promote Health (SUPPH)

| SELF CARE STRATEGY | | 1 | 2 | 3 | 4 | 5 |
|--------------------|--|------------------------|---|-----------------|---|---------------------|
| | | Very little confidence | | Quite confident | | A lot of confidence |
| Q1 | Excluding upsetting thoughts from my consciousness | | | ✓ | | |

Begin here:

| SELF CARE STRATEGY | | 1 | 2 | 3 | 4 | 5 |
|--------------------|--|------------------------|---|-----------------|---|---------------------|
| | | Very little confidence | | Quite confident | | A lot of confidence |
| Q1 | Excluding upsetting thoughts from my consciousness | | | | | |
| Q2 | Using relaxation techniques to reduce my anxiety | | | | | |
| Q3 | Finding ways of alleviating my stress | | | | | |
| Q4 | Using a specific technique to manage my stress | | | | | |
| Q5 | Doing things that helped me to cope with previous emotional difficulties | | | | | |
| Q6 | Practicing stress reduction techniques even when I'm feeling ill | | | | | |
| Q7 | Managing to keep anxiety about my illness from becoming overwhelming | | | | | |
| Q8 | Thinking of myself as better off than people who became ill when they were younger than me | | | | | |
| Q9 | Focusing on things not associated with my illness as a way of decreasing my anxiety | | | | | |
| Q10 | Believing that using a technique to manage treatment stress will actually work | | | | | |
| Q11 | Choosing the treatments that seem right for me from those recommended by my doctor | | | | | |

Please turn over

| SELF CARE STRATEGY | | 1 | 2 | 3 | 4 | 5 |
|--------------------|---|------------------------|---|-----------------|---|---------------------|
| | | Very little confidence | | Quite confident | | A lot of confidence |
| Q12 | Making my own decision regarding treatment alternatives | | | | | |
| Q13 | Deciding for myself whether or not to have treatment | | | | | |
| Q14 | Experiencing life's pleasures since I became ill | | | | | |
| Q15 | Doing special things for myself to make life better | | | | | |
| Q16 | Convincing myself I can manage the treatment stress | | | | | |
| Q17 | Helping other people going through illness and treatment | | | | | |
| Q18 | Convincing myself the treatment is not so bad | | | | | |
| Q19 | Keeping my stress within healthy limits | | | | | |
| Q20 | Appreciating what is important in life | | | | | |
| Q21 | Believing I can find strength within myself for healing | | | | | |
| Q22 | Convincing myself I'll be okay | | | | | |
| Q23 | Finding a way to get through this time | | | | | |
| Q24 | Believing that I have a positive attitude about my state of health | | | | | |
| Q25 | Doing things that helped me to cope with previous physical difficulties | | | | | |
| Q26 | Doing things to control my fatigue | | | | | |
| Q27 | Finding ways of helping myself feel better if I am feeling blue | | | | | |
| Q28 | Managing the side effects of treatment so I can do things I enjoy doing | | | | | |
| Q29 | Dealing with the frustration of illness and treatment | | | | | |

Please turn over for Questionnaire 2

Questionnaire 2
The Revised Illness Perception Questionnaire (IPQ-R)

This questionnaire is split up into 3 sections; the first section asks you about side effects that you have experienced and if you think they are related to your treatment; the second section asks you about the way you feel about your illness and treatment; and the third section asks you about what you think might be possible causes of your illness. All questions ask you to tick the box that you feel best relates to your answer. Please try to answer **all** questions.

Section 1: Symptoms/side effects

Listed below are a number of symptoms or side effects that you might have experienced since you started your treatment. **For all of the side effects listed, please answer by ticking yes or no**, whether you have experienced it since starting your treatment and if you have, then please go on to answer whether or not you think it is related to your treatment. An example is shown here.

| SIDE EFFECT/SYMPTOM | | Have you experienced this symptom since you started treatment? | | Do you think this side effect/symptom is related to your treatment? | |
|---------------------|-------------|--|----|---|----|
| | | Yes | No | Yes | No |
| S1 | Pain | ✓ | | | ✓ |
| S2 | Sore throat | | ✓ | | |

Begin here:

| SIDE EFFECT/SYMPTOM | | Have you experienced this symptom since you started treatment? | | Do you think this side effect/symptom is related to your treatment? | |
|---------------------|--------------------|--|----|---|----|
| | | Yes | No | Yes | No |
| S1 | Pain | | | | |
| S2 | Sore throat | | | | |
| S3 | Nausea | | | | |
| S4 | Breathlessness | | | | |
| S5 | Weight loss | | | | |
| S6 | Fatigue | | | | |
| S7 | Stiff joints | | | | |
| S8 | Sore eyes | | | | |
| S9 | Wheeziness | | | | |
| S10 | Headaches | | | | |
| S11 | Upset stomach | | | | |
| S12 | Sleep difficulties | | | | |
| S13 | Dizziness | | | | |
| S14 | Loss of strength | | | | |

Please turn over

Section 2: How you feel about your illness or treatment

A number of statements about your illness and treatment are listed below. We would like you to indicate how strongly you agree or disagree with each statement by **ticking the box that you think best relates to your answer. Please try to answer all questions.** An example is shown here.

| VIEWS ABOUT YOUR ILLNESS/ TREATMENT | | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
|--|-----------------------------------|-------------------|----------|----------------------------|-------|----------------|
| IP1 | My illness will last a short time | | ✓ | | | |

Begin here:

| VIEWS ABOUT YOUR ILLNESS/ TREATMENT | | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
|--|---|-------------------|----------|----------------------------|-------|----------------|
| IP1 | My illness will last a short time | | | | | |
| IP2 | My illness is likely to be permanent rather than temporary | | | | | |
| IP3 | My illness will last for a long time | | | | | |
| IP4 | This illness will pass quickly | | | | | |
| IP5 | I expect to have this illness for the rest of my life | | | | | |
| IP6 | My illness is a serious condition | | | | | |
| IP7 | My illness has major consequences on my life | | | | | |
| IP8 | My illness does not have much effect on my life | | | | | |
| IP9 | My illness strongly affects the way others see me | | | | | |
| IP10 | My illness has serious financial consequences | | | | | |
| IP11 | My illness causes difficulties for those who are close to me | | | | | |
| IP12 | There is a lot which I can do to control my symptoms/side effects | | | | | |
| IP13 | What I can do determine whether my illness gets better or worse | | | | | |
| IP14 | The course of my illness depends on me | | | | | |
| IP15 | Nothing I do will affect my illness | | | | | |
| IP16 | I have the power to influence my illness | | | | | |
| IP17 | My actions will not affect the outcome of my illness | | | | | |
| IP18 | My illness will improve in time | | | | | |

Please turn over

| VIEWS ABOUT YOUR ILLNESS/ TREATMENT | | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
|--|--|-------------------|----------|----------------------------|-------|----------------|
| IP19 | There is very little that can be done to improve my illness | | | | | |
| IP20 | My treatment will be effective in curing my illness | | | | | |
| IP21 | The negative effects of my illness can be avoided by my treatment | | | | | |
| IP22 | My treatment can control my illness | | | | | |
| IP23 | There is nothing which can help my illness | | | | | |
| IP24 | The symptoms/side effects of my illness/treatment are puzzling to me | | | | | |
| IP25 | My illness is a mystery to me | | | | | |
| IP26 | I don't understand my illness | | | | | |
| IP27 | My illness doesn't make any sense to me | | | | | |
| IP28 | I understand my illness | | | | | |
| IP29 | The symptoms/side effects from my illness change a lot from day to day | | | | | |
| IP30 | My symptoms/side effects come and go in cycles | | | | | |
| IP31 | My illness is very unpredictable | | | | | |
| IP32 | I go through cycles in which my illness gets better or worse | | | | | |
| IP33 | I get depressed when I think about my illness | | | | | |
| IP34 | I get upset when I think about my illness | | | | | |
| IP35 | I get angry when I think about my illness | | | | | |
| IP36 | My illness does not worry me | | | | | |
| IP37 | Having this illness/treatment makes me feel anxious | | | | | |
| IP38 | My illness makes me feel afraid | | | | | |

Please turn over

Section 3: Causes

This section asks you about what you think caused your illness. Some possible causes are listed below. We would like you to indicate how strongly you agree or disagree with each possible cause by **ticking the box that best relates to your answer. Please try to answer all questions.** An example is shown here.

| VIEWS ABOUT YOUR ILLNESS/ TREATMENT | | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
|--|-----------------------------------|-------------------|----------|----------------------------|-------|----------------|
| C1 | Stress or worry | | ✓ | | | |
| C2 | Hereditary – it runs in my family | | | | ✓ | |

Begin here:

| VIEWS ABOUT YOUR ILLNESS/ TREATMENT | | Strongly disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
|--|---|-------------------|----------|----------------------------|-------|----------------|
| C1 | Stress or worry | | | | | |
| C2 | Hereditary – it runs in my family | | | | | |
| C3 | A germ or virus | | | | | |
| C4 | Diet or eating habits | | | | | |
| C5 | Chance or bad luck | | | | | |
| C6 | Poor medical care in my past | | | | | |
| C7 | Pollution in the environment | | | | | |
| C8 | My own behaviour | | | | | |
| C9 | My mental attitude e.g. thinking about life negatively | | | | | |
| C10 | Family problems or worries caused by illness | | | | | |
| C11 | Overwork | | | | | |
| C12 | My emotional state e.g. feeling down, lonely or anxious | | | | | |
| C13 | My age | | | | | |
| C14 | Alcohol | | | | | |
| C15 | Smoking | | | | | |
| C16 | Accident or injury | | | | | |
| C17 | My personality | | | | | |
| C18 | Poor immune system | | | | | |

Thank you for completing this questionnaire booklet. Please return it to Lisa in the stamped addressed envelope that has been provided for you.

Appendix 4 Example of a page from the Self Care Diary¹

SELF CARE DIARY How your control and confidence affects your self-care during chemotherapy treatment



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'Self care' refers to the activities that you carry out to prevent, control or relieve any side effects that you may experience during your treatment.

In this daily diary, we would like you to tell us about the side effects that you experience and if they interfere with your usual activities. We would also like you to tell us about the self-care activities that you did or didn't use to help you feel better.

| | |
|---------------------------|--|
| Project Number | |
| Chemotherapy Cycle Number | |

¹ All 30 pages (one page for each day) in each diary resembled the example shown in this appendix

Instructions for completing the self care diary

When to fill out the diary

We would like you to fill out the diary **every day** during your 1st, 3rd, and 6th cycles of chemotherapy for a full treatment cycle (this will be for 14 days for patients who are having treatment every two weeks and for 30 days for patients who are having treatment every 4 weeks). Please start to fill out the diary on the first day that you have your treatment and continue doing this until the day before your next treatment. It's a good idea to fill the diary out **each evening** as then you can look back on how you have felt during the whole day.

Each diary contains a new page for each day and there are enough pages for one cycle of your treatment. Each page is labelled to correspond to the week during which you should fill the diary in, for example, week 1 (the week that you start your treatment), week 2, etc, and the day n which you should fill in the diary, for example, Monday, Tuesday, etc .

You will be given a new diary for each of the three treatment cycles (1, 3 and 6) when you come to the clinic for your treatment.

How to fill out the diary

The diary is quick and simple to complete. An example has been provided for you on the first page. All questions ask you to tick a box or write a few words.

You may not experience all of the side effects or do all of the self care activities listed however please try to answer all of the questions as accurately as you can. If there are any side effects that you haven't experienced or if there are any self-care activities that you didn't try then please note that as well.

How to return the diary

Once you have finished the diary (once the full cycle is finished), please return it to Lisa Kidd in the stamped addressed envelope provided. If you have any problems filling out the diary, please contact:

Mrs Lisa Kidd
Research Student
Cancer Care Research Centre
Department of Nursing & Midwifery
University of Stirling
FK9 4LA

Telephone: 01786 84 9260
Email: lisa.kidd@stir.ac.uk

Week 1: Monday

Side Effects

1. From the list below, please tick whether you did or didn't experience any side effects today and if these interfered with your daily activities or not.

| Side effects | Did you experience this side effect today? | | Did it interfere with your daily activities? | |
|--|--|----|--|----|
| | Yes | No | Yes | No |
| Diarrhoea (more than 4 bowel movements in 24hours) | | | | |
| Feeling sick (nausea) | | | | |
| Being sick (vomiting) | | | | |
| Sore mouth or throat (mucositis) | | | | |
| Extreme tiredness (fatigue) | | | | |

2. Please list below any other side effects that you experienced

Self Care Activities

3. Did you feel confident that you could do something to help with your side effects?

YES

NO

4. Did you carry out any self-care activities today?

YES

NO

If you ticked **yes**, then please go on to answer **questions 5 and 6**.

If you ticked **no**, can you please tell us why this was...

5. Did you carry out these activities to prevent side effects from occurring or once you experienced the side effect?

To prevent side effect occurring

Once side effect had occurred

6. From the list below, for each side effect, please tick whether you tried the self-care activity or not and if it helped or not.

| SELF CARE ACTIVITY | | Did you do this today? | | If so, did it help? | |
|-----------------------|--|------------------------|----|---------------------|----|
| | | Yes | No | Yes | No |
| Diarrhoea | Watch for any changes with your bowels | | | | |
| | Take your anti-diarrhoea tablets | | | | |
| | Wash your hands and keep yourself clean | | | | |
| | Change your diet e.g. avoid spicy, fatty foods, and high fibre foods such as cereals and raw vegetables | | | | |
| | Drink plenty fluids | | | | |
| Feeling or being sick | Take your anti-sickness tablets | | | | |
| | Change your diet e.g. avoid fatty, fried foods, drink high energy drinks, and try to eat small frequent meals or snacks | | | | |
| | Relax and try some deep breathing or distraction techniques | | | | |
| Sore mouth or throat | Look for any changes in your mouth or throat or feel any soreness | | | | |
| | Use regular mouthwashes | | | | |
| | Clean teeth regularly using a soft toothbrush | | | | |
| | Use throat spray or lozenges | | | | |
| | Drink plenty fluids and keep mouth moist | | | | |
| | Change your diet e.g. avoid hard, crunchy foods such as raw vegetables and avoid spicy or very hot and cold foods and drinks | | | | |
| Extreme tiredness | Rest when you felt you needed to | | | | |
| | Exercise when you can | | | | |
| | Eat a healthy, balanced diet | | | | |

7. Please list below any other self care activities that you tried

Appendix 5 Patient Registration Form

PATIENT REGISTRATION FORM

How your control and confidence affects your self-care during chemotherapy treatment



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| | | |
|--|---------|--|
| Study identification number | | |
| Chemotherapy regime | | |
| Name and address | | |
| Postcode | | |
| Social Class | | |
| Telephone number | | |
| Estimated treatment time points: | Cycle 1 | |
| | Cycle 3 | |
| | Cycle 6 | |
| Date of birth/Age | | |
| Gender | | |
| Diagnosis/Stage of cancer | | |
| Receiving treatment for early or advanced (metastatic) cancer? | | |
| Previously received chemotherapy? | | |
| Hickman or IV Line? | | |
| Performance status | | |
| Co-morbid conditions | | |
| Social support | | |
| General comments: | | |

Appendix 6 Interview Guides I (Beginning of treatment)

INTERVIEW GUIDE I How your control and confidence affects your self care during treatment



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Pre-amble

Explanation about what we will discuss in the interview, for example, coping in relation to receiving diagnosis and beginning treatment and the importance of self care

General

How have things been for you since you were diagnosed?
How have you been coping so far?
Have you tried any new ways of coping?

Treatment

How do you feel about starting treatment?
How do you think you will you cope with side effects?
How do you think your treatment will affect you and your daily routines?
Is there anything else in relation to your physical health or emotional health that you wish to discuss?

Self Care

Recap the explanation of self care
What does self care mean to you?
How important is self care to you? Why?
How do you think self care will help you to cope?
Do you have any ideas at the moment about what you could do to help with your side effects?
What kind of information have you been given about how to manage your side effects?

Control and Self Efficacy

How much control do you feel you have over what happens during your treatment?
How much control do you feel in relation to self-care?
Is having control over your self care important to you?
How confident do you feel at the moment?
How confident do you feel in being able to take control over your self care?

Appendix 7 Interview Guides II (End of treatment)

INTERVIEW GUIDE II How your control and confidence affects your self care during treatment



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Pre-amble

Explanation about what we will discuss in the interview, for example, coping during treatment, kinds of self care carried out by patients, importance of self care during treatment.

Treatment

Looking back on your treatment, how have things been for you during your treatment?

How you have felt about your treatment and how you feel about it now?

How you have coped during your treatment?

What kinds of things have you tried to help you cope with your treatment?

What kinds of side effects did you experience?

How did your treatment or side effects affect your and your daily routines?

Is there anything else that you wish to discuss in relation to your treatment

Do you have any particular concerns or worries at the moment?

Self-Care

What did self care mean for you during treatment?

What kinds of things did you do for the side effects that you experienced? (Link with diary information on the use of self care activities)

Why did you carry out self care?

Is self-care important to you? Why?

Did you find your self care useful? Why?

Control and Self Efficacy

Did you feel you had control over your self care during your treatment?

How did you take control?

Was having some control important to you?

Did your feelings of control change during your treatment? If so, how?

How did self care help with your feelings of control?

How confident did you feel to carry out self care during your treatment?

Did your confidence change during treatment? If so, how?

| Example synopsis chart of Theme: Emotional Self Care Strategies (beginning of treatment) | |
|---|--|
| Sub theme | Cluster |
| Learning what to expect | <ul style="list-style-type: none"> - knowing your body and knowing how it works - seeking information - sharing experiences with fellow patients |
| Maintaining normality | <ul style="list-style-type: none"> - continuing with normal activities - not giving up the things you enjoy doing - maintain your sense of self - care for your family - limiting adverse effects of chemo on lifestyle |
| Rationalising and comparing | <ul style="list-style-type: none"> - perceiving themselves to be lucky that their cancer had been 'found' - believing treatment to be necessary - viewing treatment as short term - believing in the efficacy of the treatment - believed that treatment would give chance of cure - viewing side effects as temporary or a 'small price to pay' - comparing own situation to others around them - diagnosis triggered period of transformation, looking for positive change |
| Not dwelling | <ul style="list-style-type: none"> - not worrying about things before they happen - deal with things as and when they arise - taking things a day at a time - not focussing on the future - not dwelling on the present, getting on with things - using techniques to relax and manage anxiety, keeping busy |
| Beating the cancer | <ul style="list-style-type: none"> - focussing on survival - fighting spirit - talking positively of the future - staying positive - belief in the efficacy of medications |
| Avoiding the outside world | <ul style="list-style-type: none"> - avoiding contact with family and friends - taking more time to yourself - avoiding going out in public - avoiding having to disclose that they were undergoing treatment, e.g. hiding hair loss |

Appendix 9 Example synopsis chart of themes for each patient

| Summary Chart of Themes from interviews at beginning of treatment | | |
|--|---|---|
| Patient | Theme: Physical Self Care Strategies | Theme: Emotional Self Care Strategies |
| 1 | <ul style="list-style-type: none"> - Treating side effects - Relying on health professionals - Adapting to side effects - Giving yourself the best chance | <ul style="list-style-type: none"> - Learning what to expect - Maintaining normality - Rationalising and comparing - Not dwelling |
| 2 | <ul style="list-style-type: none"> - Treating side effects - Relying on health professionals - Adapting to side effects - Giving yourself the best chance | <ul style="list-style-type: none"> - Learning what to expect - Maintaining normality - Rationalising and comparing - Not dwelling - Beating the cancer - Avoiding the outside world |
| 11 | <ul style="list-style-type: none"> - Treating side effects (medication only) - Relying on health professionals | <ul style="list-style-type: none"> - Learning what to expect - Maintaining normality - Rationalising and comparing - Not dwelling |

| Summary Chart of Themes from interviews at end of treatment | | |
|--|--|--|
| Patient | Theme: Physical Self Care Strategies | Theme: Emotional Self Care Strategies |
| 1 | <ul style="list-style-type: none"> - Adapting to side effects - Treating side effects | <ul style="list-style-type: none"> - Rationalising and comparing - Maintaining normality - Learning what to expect - Not dwelling |
| 2 | <ul style="list-style-type: none"> - Adapting to side effects - Treating side effects - Relying on health professionals | <ul style="list-style-type: none"> - Rationalising and comparing - Maintaining normality - Learning what to expect - Not dwelling - Focussing on the future |
| 11 | <ul style="list-style-type: none"> - Adapting to side effects - Treating side effects - Relying on health professionals | <ul style="list-style-type: none"> - Rationalising and comparing - Maintaining normality - Not dwelling - Focussing on the future |

| Patient | 'Quantitised' category for medication use at beginning/end of treatment | Qualitative Theme | Quotes to illustrate patients perceptions towards and use of medications during treatment |
|---------|---|-----------------------|---|
| 1 | Anti-diarrhoea tablets: <i>Low/Low</i> Anti-emetic tablets: <i>Low/Low</i> | Treating side effects | "I've got anti-sickness pills, I've got anti-diarrhoea pills, mouthwashes for mouth ulcers which seems to be about the normal." (Interview 1) "If I'm feeling sick, I'll take the tablets and get on with it." (Interview 2) |
| 2 | Anti-diarrhoea tablets: <i>Low/Low</i> Anti-emetic tablets: <i>Low/Low</i> | Treating side effects | "I suppose if I do feel sick, I'm just hoping that the anti-sickness tablets they've given me is going to work and if not, apparently I've got to go to the doctor...perhaps he'll prescribe something else." (Interview 1) "I knew because I had the mouthwashes...I knew I could control the mouth, that it wouldn't get to a stage that it did that first month." (Interview 2) |
| 11 | Anti-diarrhoea tablets: <i>Low/Low</i> Anti-emetic tablets: <i>Low/Low</i> | Treating side effects | "I think you've only got two options...medication, and if that doesn't work then seek advice." (Interview 1) "It's just the fourth, fifth and sixth one that sort of brought me down a wee bit you know...a wee bit more 'what will I do'...I've got these pills here I just take for diarrhoea, 'what will I do for nausea', I'll just take these oils and if I felt that these werenae working, I'd just phone [the nurse]." (Interview 2) |
| 17 | Anti-diarrhoea tablets: <i>Low/Low</i> Anti-emetic tablets: <i>Low/Low</i> | Treating side effects | "I've got treatment there if I've got any diarrhoea or anything...I can get remedies for anything that happens to me." (Interview 1) "They [the doctors] supply tablets for diarrhoea. I just took tablets for diarrhoea." (Interview 2) |
| 19 | Anti-diarrhoea tablets: <i>Low/Med</i> Anti-emetic tablets: <i>Low/Low</i> | Treating side effects | "I've had absolutely no sickness...constipated...I've got stuff from the doctor for that as well. My mouth was really but obviously what you do is go to the doctor. He's given me tablets in case it comes back again." (Interview 1) "[I had]...sore mouth at times but I just got tablets...the hospital gave me tablets. I had senna for the constipation and loperamide and domperidone [for the sickness]. I didn't take anything to ward it off, I just waited till the came on and then took it and they more or less worked...everything they gave you worked." (Interview 2) |
| 22 | Anti-diarrhoea tablets: <i>Low/Low</i> Anti-emetic tablets: <i>Low/Low</i> | Treating side effects | "I didn't feel great but I felt I knew I could get the anti-sickness tablets, mouthwashes and things like that." (Interview 2) |

Appendix 11 ECOG Performance Status Scale

| Grade | ECOG |
|-------|---|
| 0 | Fully active, able to carry on all pre-disease performance without restriction |
| 1 | Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work |
| 2 | Ambulatory and capable of all self care but unable to carry out any work activities. Up and about more than 50% of waking hours |
| 3 | Capable of only limited self care, confined to bed or chair more than 50% of waking hours |
| 4 | Completely disabled. Cannot carry on any self care. Totally confined to bed or chair |
| 5 | Dead |

These scales and criteria are used by doctors and researchers to assess how a patient's disease is progressing, assess how the disease affects the daily living abilities of the patient, and determine appropriate treatment and prognosis (http://www.ecog.org/general/perf_stat.htm, last accessed March 2007).

