

**Mental Adjustment to Colon Cancer:  
A Socio-Cognitive Approach**

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# **Abstract**

## **Introduction**

Mental adjustment to cancer is one of the important factors correlating with quality of life and psychological distress. Accurate assessment of mental adjustment to cancer and changes across the course of disease are important. Psychological morbidity associated with cancer has been shown in many studies and the coping strategies employed are important determinants of such morbidity. Adjustment to cancer can be assessed using Bandura's Socio-Cognitive Theory (SCT) to conclude which adjustment dimensions lead to learn how to live with cancer. Accordingly, the focus of this study was to explore changes in mental adjustment to the diagnosis of colon cancer over time and to identify how these adjustment dimensions are correlated with SCT's constructs.

## **Method**

A convergent mixed methods approach was chosen and data were collected over a 6 month period. Qualitative and quantitative data were collected at two time points: after surgery and 4-6 months after surgery and in the interviews participants were asked to reflect their adjustment responses immediately after diagnosis, while awaiting surgery, immediately after surgery, a few weeks after surgery and 4-6 months later. Through semi-structured interviews, the concepts of the study, mental adjustment to cancer, self-efficacy, self-regulation, outcome expectations, social support and general health status were explored. The same constructs were explored quantitatively through the Mini-Mac Scale, Self-Efficacy Scale, Cognitive Emotion Regulation Questionnaire (CERQ), Revised Life Orientation Test (LOT-R), Multidimensional Scale of Perceived Social Support (MSPSS) and SF-12V2 Health Survey. Directed (deductive) content analysis was completed with the qualitative data and descriptive and analytic statistics were used to explore differences over time and relationships between constructs within quantitative data.

## **Results**

A total of sixteen and twelve participants were interviewed at time point one and time point two, respectively. All participants were New Zealand Europeans, most were male (62% &

58%) and over seventy years old (56% & 58%). The majority of participants were married (56%) and living with their husband/wife or partner (44% & 50%). More than half of the sample showed a religious affiliation (56.25% & 58.32%). After receiving the diagnosis of colon cancer, the most frequently demonstrated adjustment response were 'Anxious preoccupation' whereas a 'Fighting spirit' response was the most frequently demonstrated one both after surgery and 4-6 months after surgery. The responses of 'Anxious preoccupation' and 'hopelessness/helplessness' decreased over time, but the 'Fatalism' response was increased over time. High to moderate self-efficacy status was correlated with a 'Fighting spirit' response while 'Hopelessness/helplessness', 'Anxious preoccupation' and 'Fatalism' were correlated with low self-efficacy. A 'Fighting spirit' response was more common among participants who reported task perception, setting goals and enacting self-regulation efforts. 'Optimistic expectations' was correlated to 'Fighting spirit' and 'Fatalism' responses whereas 'Uncertainty' was mostly correlated with 'Anxious preoccupation', 'Hopelessness/helplessness' and 'Fatalism'. The majority of participants with high perceived social support participants reported a 'Fighting spirit' adjustment response.

A total of 20 participants completed the questionnaires at both time points. The level of "Anxious preoccupation" dramatically decreased 4-6 months after surgery. High levels of self-efficacy were correlated with lower levels of "Fatalism" and high levels of optimism were correlated with low levels of "Fatalism" and "Hopelessness/helplessness". Overall, higher levels of positive refocusing and acceptance were reported 4-6 months after surgery.

## **Discussion**

The study suggests that post treatments participants demonstrated less 'anxious preoccupation' and 'hopelessness/helplessness'; however, some levels of uncertainty remained and many had a fatalistic outlook. Participants who demonstrated high self-efficacy were more determined to fight the illness and saw cancer as a challenge; conversely, participants who were unsure if they could manage this new situation described feeling hopeless and anxious and expressed a fatalistic view. The findings suggest that when participants set goals to get over the cancer and get back to normal life, they were more likely to adopt a 'fighting spirit' adjustment response. The commitment to goals, accepting limitations and changing life style were associated with this adjustment response. Optimistic expectations were linked to a 'fighting spirit' response in the present study, while feeling uncertain about outcome expectations was accompanied by 'hopelessness/helplessness' and 'anxious preoccupation' responses. High perceived social

support, described as social connections (marriage, friendship or membership of religious groups) were helpful in managing the new situation providing empathy and caring, offering service or even companionship. Participants with high perceived social support were more likely to demonstrate a 'Fighting spirit' response and therefore a more positive mental adjustment to cancer.

Despite the limitations inherent within the study, this research has contributed to knowledge on mental adjustment to colon cancer over time using a socio-cognitive approach. The results have significant implications for healthcare professionals and policy-makers around the allocation the psycho-oncological services for people with newly diagnosed colon cancer patients in working towards supporting mental adjustment.

**Conference paper and poster presentation from this study:**

*Mental adjustment to colon cancer: a socio-cognitive approach.* Paper presented at the world congress on nursing, Dubai, UAE, November 2015

*Outcome expectations and mental adjustment to colon cancer after surgery: A qualitative approach.* Poster presented at the world congress on nursing, Dubai, UAE, November 2015

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*The will to win, the desire to succeed, the urge to reach your full potential... these are the keys that will unlock the door to personal excellence.*

**Confucius**

*I am a survivor and not a victim. Life isn't perfect. When you get a knock, you have to get up, dust yourself down and get on with it...*

*Patsy Kensit*

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# **Introduction and background**

## **Introduction**

Distress associated with the diagnosis and ongoing management of cancer has led to recognize it as the sixth vital sign in cancer care (Carlson, Groff, Maciejewski, & Bultz, 2010). The diagnosis of cancer has the highest risk of changing psychological functioning in comparison to other health-related diagnoses (Polsky et al., 2005). Although psychological distress following a diagnosis of cancer is anticipated, the assessment and management of patients' psychological needs have remained as a challenge throughout the cancer journey (Absolom et al., 2011; Merckaert et al., 2010). The term 'mental adjustment' refers to cognitive and behavioral responses in the face of a diagnosis of cancer (Greer & Watson, 1987; Watson et al., 1988) and is a change from one state to another (Brennan, 2001). Psychological responses and mental adjustment to cancer have been suggested to influence many health-related factors (Cordova et al., 2003; Johansson, Rydén, & Finizia, 2011), and mental adjustment changes over time have been shown to be related to psychological symptoms and emotional well-being (De Fazio et al., 2013; Nordin & Glimelius, 1998). However, there is a gap as to what is defined as optimal mental adjustment among cancer patients. Many studies have assessed the initial period of adjustment but fewer studies have followed it up for long term periods. Stable and declining patterns of change over time in adjustment to diagnosis of cancer have been reported by most longitudinal quantitative studies; however, there are very few in-depth qualitative follow-up designs. The literature has documented a variety of personal, environmental and behavioural factors to predict and interpret mental adjustment to cancer (Akechi, Kugaya, et al., 1998; Cicero, Lo Coco, Gullo, & Lo Verso, 2009; Hulbert-Williams, Neal, Morrison, Hood, & Wilkinson, 2012), but the lack of an underpinning theory is evident. Bandura's socio-cognitive theory (SCT) has been used to enhance health behaviours and adjustment to chronic illnesses and it can be an effective framework in increasing and even maintaining positive health behavior (Bandura, 1997). The three components of the SCT are self-efficacy, outcome expectations and self-regulation; they have been considered as the predictors of positive change in psycho-oncology in term of quality of life (Graves, 2003). The impact of self-efficacy has been well reported in oncology; however, it seems that the value of outcome expectations and self-regulation deserve additional study especially in relationship to adjustment to the diagnosis of cancer. There is no study in New Zealand to

explain how New Zealanders learn to live and adjust with a diagnosis of cancer. According to statistics, colorectal cancer is the most common cancer in New Zealand and living with cancer would be a challenge. Accordingly, this thesis examines the changes of mental adjustment to colon cancer after diagnosis over a 4-6 month period. Using an in-depth qualitative approach, accompanying a supporting quantitative design through socio-cognitive theory lens, would help bring about a better understanding of mental adjustment to cancer over time in the New Zealand context.

This chapter presents the background to the diagnosis of colon cancer and the treatments for localized disease. The importance of mental adjustment to cancer is explored and the chapter concludes with an outline of the thesis.

## **A diagnosis of colon cancer**

Cancer is the uncontrolled growth of cells that can invade and spread to the other sites of body and has severe health consequences (WHO, 2015) . Colon cancer is described as a preventable and curable disease which is known to be influenced by genetic and environmental factors such as micronutrients, exercise and obesity and ninety percent of disease occurs in the individuals who are aged 50 and older. It develops as the result of an accumulation of genetic mutations and evolves through a multistep process from a benign adenomatous polyp that eventually becomes cancerous; which can take approximately 10 years (Yarbro, Wujcik, & Gobel, 2010). Colorectal cancer may be diagnosed through symptom report or through screening programs. Symptoms of colorectal cancer may be intermittent abdominal pain, nausea and vomiting, a palpable mass, red blood mixed with stool, melena, iron deficiency, obstruction and perforation. The diagnostic strategies include instrumental and pathologic assessment like endoscopy, radiological techniques and biological markers exploration (Labianca et al., 2010).

In 2012, an estimated 14.1 million new cases of cancer were reported worldwide and the four most common cancers occurring worldwide were lung, female breast, bowel and prostate cancer ("Worldwide cancer statistics," 2015). In 2012, there were 21,814 new cases of cancer registered in New Zealand and the most commonly registered cancers were prostate (3129 cases), breast (3054), colorectal (3016), melanoma (2324) and lung (2027). There were 8905 deaths due to cancer in New Zealand in 2012 ("Cancer: New registrations and deaths 2012," 2015).

The prognosis of colon cancer is directly related to the stage of the disease at the time of diagnosis (Yarbro et al., 2010). The stage 0 colon cancer (TisN0M0) is the most superficial one and is treated by local excision or segmentomy resection for large lesions. Stage I colon cancer (T2N0M0) has a high cure rate and the standard treatment option is wide surgical resection and anastomosis. Stage II colon cancer (T3N0M0 or T4N0M0) needs wide surgical resection with anastomosis and adjuvant chemotherapy following surgery. In stage III (any TN1M0 or any TN2M0) the lymph nodes are involved and the number of lymph nodes is related to the prognosis. The treatment would be a wide surgical resection and anastomosis and post-operative chemotherapy is indicated (Labianca et al., 2010).

Surgery is the primary treatment for colon cancer to eliminate disease in the colon, nodal basins and contiguous organs. The procedure is a colectomy with removal of regional lymph nodes. Potential complications of colorectal surgery might be anatomical leak, intra-abdominal abscess, bowel obstruction, alterations in bowel elimination pattern, alteration in urinary elimination, sexual dysfunction and stoma dysfunction (Yarbro et al., 2010). Adjuvant therapy after surgery aims to destroy the remaining tumor cells and to reduce the risk of recurrence of the disease (Demols & Van Laethem, 2002). Patients receiving chemotherapy find a variety and unpredictability of side effects which are difficult to cope with (Dikken & Sitzia, 1998). Adjuvant chemotherapy has improved the survival. The colon cancer survivors need long-term follow-up, health maintenance and life-style modifications (Denlinger & Barsevick, 2009). High levels of distress are expected among most cancer patients receiving chemotherapy. It is an unpleasant emotional experience which interferes with coping with the disease (Zainal, Hui, Hang, & Bustam, 2007). The start point of chemotherapy triggers this distress which is mostly related to side effects of chemotherapy. These side effects affect quality of life (Faul, Jim, Williams, Loftus, & Jacobsen, 2010).

The start of chemotherapy has the potential to trigger significant distress. The source of this distress includes the side effects of chemotherapy. These side effects disrupt daily activities and daily functioning (Yarbro et al., 2010).

### **The importance of mental adjustment to cancer**

The term adjustment to cancer refers to the absence of psychological morbidity and a return to premorbid functioning (Hatchett, Friend, Symister, & Wadhwa, 1997). Mental adjustment to cancer is one of the important factors correlating with quality of life and psychological distress. Some studies have shown that it may even affect physical outcomes (Akechi, Kugaya, et al.,

1998). Accurate assessment of mental adjustment to cancer is important, because psychological morbidity associated with cancer has been shown in many studies, and the type of coping strategies employed are important determinants of psychological morbidity (Moorey & Greer, 1989; Watson, Greer, Blake, & Shrapnell, 1984). Psychological response to cancer may also affect the duration of survival (Watson, Haviland, Greer, Davidson, & Bliss, 1999). It has been suggested that the construct of mental adjustment is related to the medical and psychological outcome in cancer patients (Watson et al., 1988).

Most people diagnosed with cancer experience some level of distress during the course of their disease (Hulbert-Williams et al., 2012). Previous literature shows that diagnosis of cancer accompanied by sense of threat and uncertainty and anxiety could be a result of fear of suffering and death (Gil, Costa, Hilker, & Benito, 2012). Adjustment is a change from one state to another over time (Heim, Valach, & Schaffner, 1997; Helgeson, Snyder, & Seltman, 2004; Johansson et al., 2011; Nordin & Glimelius, 1998). Mental adjustment and coping impact on quality of life for people diagnosed with cancer; however, different dimensions of adjustment have different outcomes (Ferrero, Barreto, & Toledo, 1994). Adjustment responses such as a fighting spirit might be beneficial, whereas hopelessness/helplessness impacts on quality of life negatively (Ferrero et al., 1994). There is an ongoing debate on the possible impacts of responses such as avoidance, fatalism and anxious preoccupation on quality of life and mental health (Nordin & Glimelius, 1998). The correlation between mental adjustment and death, and survival and recurrence is controversial (Cordova et al., 2003; Ganz et al., 2003; Grassi, Travado, Moncayo, Sabato, & Rossi, 2004).

Adjustment to colon cancer is a process of appraisal, coping efforts and adaptation to the diagnosis of cancer, its treatments and the uncertainty about the future (Hoffman, Lent, & Raque-Bogdan, 2013). The changing nature of colon cancer and its treatments affect cognitive appraisals and adjustment responses over time and the efficacy of different adjustment responses may vary at different time points. Thus, the changing status at different time points should be considered when mental adjustment to cancer is investigated (Johansson et al., 2011).

Many theories have described the impacts of both cognitive and social factors on health behaviors and adjustment to chronic illnesses, and Bandura's socio-cognitive theory is one of them (Bandura, 1998). The SCT considers personal, behavioral and environmental factors to adjust to a new situation (Bandura, 2011). The adjustment responses can be predicted by three components of SCT including self-efficacy, self-regulation and outcome expectations. Social

support can be assessed as the environmental factor (Bandura, 1998). The impacts of self-efficacy and social support have been well reported in oncology; but it seems that the value of outcome expectations and self-regulation deserve additional studies especially in relation to adjustment to a diagnosis of cancer (Graves, 2003).

Therefore, this study aims to explore changes in mental adjustment to the diagnosis of colon cancer over time and to identify how these adjustment dimensions are correlated with socio-cognitive theory constructs. The mechanisms of psychosocial changes can be evaluated through SCT's components of self-efficacy, outcome-expectations and self-regulation. This theoretical lens provides a framework for this study; hence, self-efficacy, self-regulation, outcome-expectancy and perceived social support are assessed and the correlations between these concepts and mental adjustment to cancer are explored.

It is hoped that findings from this mixed method research will assist in improving mental adjustment to colon cancer as the leading cancer in New Zealand. A better understanding of adjustment to cancer will contribute to knowledge on interventions to improve quality of life, the main focus in psycho-oncology.

The structure of the thesis is detailed below.

### ***Chapter 2: Literature review***

This chapter examines the existing literature related to mental adjustment to a diagnosis of colon cancer through Bandura's socio-cognitive theory. All the literature relevant to coping and mental adjustment to cancer assessment focusing on its changes over time and all studies relevant to constructs of self-efficacy, self-expectations, self-regulation and social support are discussed. The chapter summarizes all key findings from previous studies and the areas for exploration as addressed by this study.

### ***Chapter 3: Methodology and methods***

This chapter sets out the methodology and methods used in the thesis. An overview of pragmatism will be set out and its relevance to mixed methods research. Mixed methods research will be introduced, including key researchers, and the strengths and limitations of the approach before focusing on Creswell's (2011) embedded mixed methods research design. Here the concepts of socio-cognitive theory are also outlined. The research methods will describe the process employed in conducting the study.

#### ***Chapter 4: Qualitative results***

This chapter presents findings from the interviews with participants exploring changes of mental adjustment strategies over time in relation to the constructs of socio-cognitive theory. The participants' demographic data are provided and themes arising from the interviews are described and illustrated. The themes are presented in chronological order including immediately after receiving diagnosis of colon cancer, awaiting surgery, immediately after surgery in hospital setting, before starting adjuvant chemotherapy and 4-6 months after surgery.

#### ***Chapter 5: Quantitative results***

This section describes participant demographics and then presents the findings for each questionnaire over time and correlations with the constructs of socio-cognitive theory.

#### ***Chapter 6: Discussion and conclusion***

This chapter begins with a summary of the key findings before discussing the meaning and importance of the findings within the wide context. The clinical relevance of the findings are presented. The study's limitations are acknowledged, followed by suggestions for further research and an overall conclusion.

## **Chapter two**

### **Literature review**

#### **Introduction**

This chapter examines the existing literature related to mental adjustment to a diagnosis of colon cancer. Firstly, the impacts of a diagnosis of cancer as a threat and its links to psychological distress are described. Secondly, the colon cancer and specifically the treatments of a localized disease will be discussed. In the next part, the definition, dimensions, predictors and impacts of mental adjustment to cancer are presented. All the literature relevant to coping and mental adjustment to cancer assessment focusing on changes over time are explored. Finally, Bandura's socio-cognitive theory (SCT) is introduced with all researches relevant to the three constructs of self-efficacy, self-regulation and outcome expectations. Social support is presented as the environmental factor of SCT and a possible predictor of mental adjustment. This chapter summarizes all key findings from previous studies and identifies areas requiring further exploration.

#### **Impact of a diagnosis of cancer**

The experience of high levels of distress and psychological symptoms are common among people who receive a diagnosis of cancer (Carlson et al., 2010; Fang, Fall, Mittleman, Sparén, et al., 2012; Mehnert & Koch, 2007; Turner, Kelly, Swanson, Allison, & Wetzig, 2005). The diagnosis of cancer represents a stressful event which may generate fear, uncertainty, distress and psychosocial needs (Merckaert et al., 2010). The rate of psychological distress in people with newly diagnosed cancer is variable and has been found to be high among women, younger patients and in recurrent or metastatic disease (Gil et al., 2012; Lynch, Steginga, Hawkes, Pakenham, & Dunn, 2008; Turner et al., 2005). In a large nationwide cohort study of persons who received cancer diagnosis in Sweden, an increased risk of suicide, or death from cardiovascular causes, within the first weeks of diagnosis were reported (Fang, Fall, Mittleman, Sparén, et al., 2012). Similarly, a randomized, controlled trial screening for distress in lung and breast cancer outpatients reported a high prevalence of baseline distress across patients (Carlson et al., 2010). Gil et al. (2012) stated that anxiety is the symptom that characterizes diagnosis and it is more common among women. A large scale psychological screening

reported that 19.0% of cancer patients showed clinical levels of anxiety and 12.9% reported clinical symptoms of depression after diagnosis (Linden, Vodermaier, MacKenzie, & Greig, 2012).

Distress refers to a range of negative psychosocial outcomes and poor quality of life (Gao, Bennett, Stark, Murray, & Higginson, 2010; Hulbert-Williams et al., 2012). It is defined as an unpleasant experience of psychological, social and/or spiritual nature, which varies from normal feelings of vulnerability, sadness and fears to disabling problems such as depression, anxiety, social isolation and spiritual crisis (Gil et al., 2012). For this reason, emotional distress is recognized as the sixth vital sign in cancer care (Gil et al., 2012; Linden et al., 2012). In a large prospective survey of psychological distress among Australian colorectal cancer patients, Lynch et al. (2008) found that over 8.3% and 6.7% of respondents reported experiencing distress 6 and 12 months after the diagnosis of cancer respectively. Factors such as distress levels at 6 months after diagnosis, comorbidities, optimism, cancer threat appraisal and social support were shown to be significantly associated with distress levels at 12 months after surgery.

The psychosocial distress has been known as a challenge and cancer patients still report unmet needs and a desire for psychological support (Absolom et al., 2011). Screening for symptoms of distress may identify people who require psychological interventions (Lynch et al., 2008). Further exploration of the predictors of negative psychosocial outcome of cancer diagnosis may help to monitor people with adjustment difficulties who require special consideration (Gil et al., 2012; Hulbert-Williams et al., 2012). Approximately one in five people newly diagnosed with cancer have not attended counselling and further studies are needed into the barriers to the provision and uptake of psychosocial support (Nekolaichuk, Cumming, Turner, Yushchyshyn, & Sela, 2011). Unmet psychological needs may be identified through psychological assessment of distress (Gao et al., 2010).

## **The diagnosis of colon cancer**

Colon cancer has been described as a preventable and curable disease. The evolution from a benign adenomatous polyp to a cancerous tumour can take approximately 10 years (Yarbro et al., 2010). New Zealand has one of the highest bowel cancer rates in the world. It is the second highest cause of cancer death, although it can be treated if it is diagnosed early. Colon cancer is common in the elderly particularly after age 50. It affects men more than women and a diet

rich in red meat and animal fats and low in vegetables, fruit and fibre and lack of exercise can be responsible for it ("Cancer: New registrations and deaths 2012," 2015).

The stage of the disease determines the type of treatment. Stages 0 and I are treated by surgery, while stages II and III need surgery and adjuvant chemotherapy (Labianca et al., 2010).

## **Surgical treatment**

Surgery is the primary treatment for colon cancer to eliminate disease in the colon, nodal basins and contiguous organs. The procedure is a colectomy with removal of regional lymph nodes. Potential complications of colorectal surgery might be anatomical leak, intra-abdominal abscess, bowel obstruction, alterations in bowel elimination pattern, alteration in urinary elimination, sexual dysfunction and stoma dysfunction (Yarbro et al., 2010).

The short-term morbidity and mortality are more common between the risks of surgery, especially for elderly cancer patients. A retrospective cohort study of functional status and mortality rates after colon cancer surgery in older nursing home residents found that mortality and sustained functional decline are common (Finlayson et al., 2012). Whynes and Neilson (1997) studied general health status, symptoms and emotional reactions before and 3 months after surgery for colorectal cancer. More than 80% of patients reported the presence of anxiety, worry and nervousness before the surgery, whilst the commonly reported symptoms at three months after surgery were tiredness, wind and lack of energy. The symptoms' prevalence decreased significantly three months after surgery.

In a qualitative descriptive study, the experience of life in the first year after surgery was explored from the perspective of persons treated for colorectal cancer, and their partners. The participants described living a normal but different life after colorectal surgery (Ohlsson-Nevo, Andershed, Nilsson, & Anderzén-Carlsson, 2012). Moderate levels of uncertainty, low levels of symptom distress (pain, fatigue, constipation, diarrhoea and loss of appetite) and a moderate number of discharge information needs have been reported by patients after a colon resection for cancer (Galloway & Graydon, 1996). In a descriptive longitudinal study in Taiwan, 35 colorectal cancer patients after surgery took part in a structured interview 1 week, and 1, 2 and 3 months after colorectal cancer surgery. The results showed that the distress level of diarrhoea is at its highest 1 week after surgery, but gradually decreases thereafter (Pan, Tsai, Chen, Tang, & Chang, 2011). In the US, Northouse, Mood, Templin, Mellon, and George (2000) interviewed 56 couples one week after diagnosis, and 60 days and one year after colon cancer

surgery. Decreased family functioning and social support were reported by both patients and spouses; but emotional distress did decrease over time. Hopelessness and spouse role issues were the strongest predictors of patients' role adjustment problems.

The loss of energy and a severe impairment of physical performance are common in patients undergoing cancer treatments. Fatigue is a frequent problem reported after surgical treatment of cancer. This problem is related to the psychosocial situation, mood disorders and the amount of physical activity. The aerobic training program improves the physical performance of patients after surgery for cancer but it is not better than progressive relaxation training (Dimeo, Thomas, Raabe-Menssen, Propper, & Mathias, 2004).

Optimizing pre-operative care using an enhanced recovery program decreases hospital stay with no increased morbidity and deterioration in quality of life or increased cost (King et al., 2006). The hospital stay after colorectal surgery has been shortened because of better post-operative care protocols during the last decade. It is expected that laparoscopic colorectal surgery may result in an early recovery and discharge. A study of 118 discharged patients within 72 hours of laparoscopic colectomy reported lower readmission and complication rates compared to open colectomy (Delaney, 2008). Increased readmission rates have been reported during the past two decades (Schneider et al., 2012). Hendren, Morris, Zhang, and Dimick (2011) assessed whether early hospital discharging increases readmission rates on patients 65 and older undergoing colectomy surgery for cancer. The results showed that early discharge does not have a higher readmission rate.

The primary surgical procedure may affect both anatomical and functional status. Emotional and physical self-care strategies should be supported to help the patients' independence (Yarbro et al., 2010).

### **Adjuvant chemotherapy**

Chemotherapy has a significant role in colon cancer management. Chemotherapy is recommended for all patients with stage III colon cancer and for patients with high risk stage II disease (Yarbro et al., 2010). Adjuvant therapy after surgery aims to destroy the remaining tumour cells and to reduce the risk of recurrence of the disease (Demols & Van Laethem, 2002). The scope of chemotherapeutic drugs is limited by the side effects of chemotherapy. A study on 100 subjects with multiple carcinomas showed that patients were suffering from headache (43%), fatigue (90%), weakness (95%), hair loss (76%), nausea (77%), vomiting (75%),

diarrhoea (31%), abdominal cramps (40%), mouth sores (47%), dry mouth (74%), memory impairment (14%) and numbness (44%) (Aslam et al., 2014). Patients receiving chemotherapy find the variety and unpredictability of side effects difficult to cope with. Using a self-report questionnaire listing 61 possible side effects, 12 patients with colorectal cancer receiving 5-fluoracil + folinic acid chemotherapy reported side effects following each cycle of chemotherapy. Fatigue was the most common side effect (97%); however, mouth ulceration was reported as the worst side effect (Dikken & Sitzia, 1998).

The use of adjuvant chemotherapy has improved survival. The improved treatments result in the potential late or long-term side effects that can affect quality of life. The colon cancer survivors need long-term follow-up, health maintenance and life-style modifications (Denlinger & Barsevick, 2009).

The efficacy and toxicity of adjuvant chemotherapy after colon surgery are controversial for colon cancer patients more than 70. In a pooled analysis involving 3351 patients in 4 age categories, the effects of adjuvant chemotherapy were compared to surgery alone in stage II or III colon cancer. Adjuvant treatment had a positive effect on both survival and time to tumour recurrence. This study suggested that elderly patients can receive the same benefit from adjuvant chemotherapy without a significant increase in toxic effects (Sargent et al., 2001).

Most cancer patients receiving chemotherapy experience high levels of distress. Distress is a multifactorial, unpleasant emotional experience of psychological, social and/or spiritual nature, and it interferes with the ability to cope with the disease (Zainal et al., 2007). The start of chemotherapy has the potential to trigger significant distress. The source of this distress includes the side effects of chemotherapy; these side effects disrupt daily activities and daily functioning (Faul et al., 2010).

## **Mental adjustment to cancer**

The term adjustment to cancer refers to the absence of psychological morbidity and retuning to premorbid functioning (Hatchett et al., 1997). Adjustment is a change from one state to another; however, research has mostly focused on the end point rather than the process of change (Brennan, 2001).

Watson et al. (1988) used the term “mental adjustment” to refer to coping styles of individuals in the face of a diagnosis of cancer. Greer and Watson (1987) defined mental adjustment to cancer as the cognitive and behavioural responses made by an individual to the diagnosis of

cancer. Nordin, Berglund, Terje, and Glimelius (1999) illustrated that this definition is different from the definition of coping of Lazarus and Folkman (1984). They stated that coping is a wilful cognitive or behavioural effort, while the mental adjustment could be involuntary emotional reactions to threatening events. In mental adjustment, the cognitive appraisal and the ensuing reactions cannot be differentiated.

Coping and mental adjustment are widely studied in psychosocial research with cancer; however, these concepts are often not well defined (Nordin et al., 1999). Coping is a critical factor between a stressful event, and physiological and psychological adaptation. Lazarus and Folkman (1984) defined coping as

*Constantly changing cognitive and behavioral efforts to manage specific external or internal demands that are appraised as taxing or exceeding the resource of a person (p.141).*

Folkman (2013) defines stress as

*A situation that is appraised by the individual as personally significant and as having demands that exceed the person's resources for coping (p.120).*

The 'stress process' begins when the person starts to know a change or a threatened change in the status of current goals and concerns as to what is happening. There is an assumption that people are constantly appraising their relationship to the environment (Folkman & Greer, 2000). In primary appraisal, the person assesses what is happening and whether it matters and why, and includes the appraisal of harm or loss that has already occurred. It depends on a person's beliefs, values and goals. Folkman and Greer (2000) believe that people vary in the attributes; a given situation such as a diagnosis of breast cancer is appraised by some people as harm, by others as a threat, and by still others as a challenge. Secondary appraisal is the person's evaluation of options for coping. These options are determined both by the situation and by the person's physical, psychological and spiritual resources for coping. Stress and coping theory define two kinds of coping: problem-focused coping which uses strategies like information gathering and decision making and emotion-focused coping to regulate negative emotions, using strategies like distancing, seeking emotional support and escape-avoidance. The meaning-focused coping was introduced as the third kind of coping based on findings that positive emotions occur alongside negative emotions through stressful periods. The appraisal process determines subsequent coping. Greater control (secondary appraisal) is associated with higher levels of problem-focused coping such as information search, problem solving and

direct action to solve a problem. There is less control in emotion-focused coping such as escape and avoidance, the seeking of social support, distancing or cognitive reframing. People vary their coping based on the intensity of their emotion response and their ability to regulate it (Folkman, 2013; Folkman & Greer, 2000). Coping is one link in a complex process, contingent on appraisal which defines the personal significance of the stressful event; it is separate from its outcome, so its role in influencing the outcome should be independently assessed (Lazarus, 1993).

People react to a diagnosis of cancer through a cognitive process of appraising the nature of the stressor (e.g. threat, actual harm or loss) or if they are able to cope with it. They seek information about treatment options and their success to assess if they are adequate to meet the threat. The post-treatment appraisal is called valued goals (e.g. having a biological child), which include life-role, self-image and fundamental assumption of life. Appraisal and reappraisal occur throughout the cancer journey. The management of treatment side effects such as fatigue and physical limitations may change expectations of life. Cancer patients may grieve over their normal life before cancer, and worry about cancer recurrence, which leads to reappraising their expectations of functioning (Hoffman et al., 2013). Cancer survivors who employ high threat appraisal and low coping appraisal experience more fear of recurrence of cancer (McGinty, Goldenberg, & Jacobsen, 2012). Rand et al. (2012) suggested that illness appraisal is more consistently associated with psychological response to advanced cancer than patients or disease characteristic. Psychological well-being can be improved by helping patients to appraise their illness. The kind of appraisal may predict depression in cancer patients. The higher depressive symptoms can be predicted by appraisal of harm/loss and greater use of escape/avoidance coping in breast cancer patients (Bigatti, Steiner, & Miller, 2012).

Studies on coping in cancer have focused on three kinds of coping: problem-focused coping, emotion-focused coping and more recently, meaning making (Hoffman et al., 2013). Strategies like information gathering and decision making are problem-focused ones which are associated with greater control (secondary appraisal) of the problem. On the other hand, there is less control in emotion-focused coping which tries to regulate negative emotions using strategies like distancing, seeking emotional support and escape-avoidance (Folkman, 2013; Folkman & Greer, 2000). Stanton et al. (2000) stated that coping through an emotional approach helps adjustment and health status for breast cancer patients. They described that being able to process and express emotions are important to avoid getting caught in a pattern of rumination.

Meaning-making is another kind of coping strategy which is defined by Park et al. (2010) as the recovery of meaning or making new meaning for stressful situations. In a longitudinal study, Park et al. (2008) showed that meaning making efforts result in better adjustment by the stressful creation of adaptive meaning made from the cancer experience. Conversely, Roberts, Lepore, and Helgeson (2006) described that high levels of intrusive thoughts and searching for meaning are related to worse physical and mental functioning and more searching for meaning. Similarly, Tomich and Helgeson (2006) found that baseline perception control over illness were related to worse physical functioning and worse mental functioning 5 years later. A sense of meaning may enhance adjustment, but the processes such as rumination may actually exacerbate distress. The goals and life roles' reassessment introduce additional coping strategies. The cancer survivors should establish new life goals and life roles that are more achievable compared to the pre-cancer goals. The older cancer patients don't report changes in life goals and life roles because of other health or family concerns. In contrast, setting life goals and roles could be a challenge for younger cancer patients (Hoffman et al., 2013).

Pinquart, Nixdorf-Hanchen, and Silbereisen (2005) investigated the age effects on goal commitment in recently diagnosed cancer patients. They reported that cancer patients have a greater emphasis on goals related to social (e.g. increasing time spent with family and friends), transcendental (e.g. strengthening spirituality) and health issues rather than goals related to achievement (e.g. career success or increasing material possession) compared to healthy controls. The older patients reported a lower number of life goals, less effort to achieve their goals and greater focusing on short-term goals.

Oswiecki and Compas (1999) assessed 70 women with breast cancer near their diagnosis and at 3 and 6 months follow-up. They showed that problem-focused engagement correlated with lower anxiety and depression symptoms. The interaction of problem-focused engagement coping and perceived control was known as a significant predictor for lower anxiety/depression symptoms.

Mental adjustment has been defined as the cognitive and behavioral responses made by an individual to the diagnosis of cancer (Greer & Watson, 1987). This definition is different at least in one important respect from the definition of coping of Lazarus and Folkman (1984). Coping is a willful cognitive or behavioral effort, but mental adjustment may also include involuntary emotional reactions to threatening events. The appraisal of the threatening situation is included in the broad definition of mental adjustment. Thus in mental adjustment, cognitive

appraisal of a demanding situation is not differentiated from the ensuing reactions (Nordin et al., 1999). Mental adjustment includes first the appraisal, such as how the patient perceives the implication of cancer, and second the ensuing reactions, such as what the patient thinks and does to reduce the threat posed by the disease (Greer, Moorey, & Watson, 1989). People respond to the diagnosis of cancer in different psychological ways. Greer and Watson (1987) described a single construct called 'mental adjustment' from the combination of the appraisal process and coping responses.

### **Categories**

In a prospective 5 year study, Greer, Morris, and Pettingale (1979) used a semi-structured interviews and standard psychological tests to assess 69 early breast cancer patients' responses to the diagnosis of cancer before surgery, 3 and 12 months after surgery, and then annually for 4 years. They described four categories of psychological responses:

- Denial: the active rejection of any evidence about the diagnosis is apparent
- Fighting spirit: an optimistic attitude toward the disease and a search for more information
- Stoic acceptance: the diagnosis is accepted without any inquiry for more information. The illness and any symptoms are being ignored
- Feeling of helplessness/hopelessness: feeling ill and sometimes actually dying. Life is disrupted by cancer and impending death. There is an obvious emotional distress.

These categories provide a collection of attitudinal, intra psychic and behavioral features associated with adjustment to the diagnosis of breast cancer. In another study in Denmark by Morris, Blake, and Buckley (1985), 170 newly diagnosed patients with early breast cancer and lymphoma were interviewed 3 and 12 months after the diagnosis. Three types of responses were recognized:

- Appraisal statements: these describe patients' evaluation of their diagnosis
- Mitigating statements: these show patients' intention to manipulate their own thinking about the diagnosis
- Facilitating statements: these describe the ways patients encourage themselves to think positively without the potential harm of the cancer diagnosis on their lives

Greer and Watson (1987) developed the mental adjustment to cancer (MAC) scale using the four original categories of 'fighting spirit', 'cognitive avoidance', 'hopelessness/helplessness' and 'fatalism' with another additional category, which Watson et al. (1988) called 'anxious preoccupation'.

There is limited evidence for the role of each mental adjustment strategy in well-being and a quality of life. In a cross sectional study of 238 cancer survivors in the US, Yeung and Lu (2014b) demonstrated that a higher level of 'fighting spirit' is correlated with a higher quality of life whereas a higher level of 'fatalism' is associated with a lower quality of life. Similarly, Kershaw, Northouse, Kritpracha, Schafenacker, and Mood (2004) described active coping as a predictor for higher quality of life while avoidance is associated with lower quality of life among advanced breast cancer patients in Thailand. Previously in a longitudinal study among 68 newly diagnosed Italian breast cancer patients, Ferrero et al. (1994) reported that 'fighting spirit' and 'denial' were predictors of a better quality of life, while 'helpless/hopeless', 'anxious preoccupation' and 'fatalism' were negatively related to well-being. This study identified a strong association between mental adjustment to cancer and physical symptoms. Similarly in the US, Dukes Holland and Holahan (2003) reported that 'avoidance coping' strategies are negatively correlated with psychological well-being. Although based on these studies, there is an agreement on the role of mental adjustment, such as 'fighting spirit', 'anxious preoccupation' and 'hopelessness/helplessness' on the quality of life; however, the roles of 'fatalism' and 'cognitive avoidance' have remained unclear.

Few studies have investigated the impacts of mental adjustment categories on emotional recovery and the final adjustment outcome. A longitudinal study in Italy reported that improvement of mental adjustment to cancer is related to lower 'anxious-depressive symptoms'. Mental adjustment changing over time was shown to be related to anxiety and depression symptoms (De Fazio et al., 2013). Along the same lines, a cross-sectional study assessing global distress among 152 newly diagnosed thyroid cancer patients in Korea reported that 'anxious preoccupation' and 'helplessness/hopelessness' are the most significant factors predicting distress (Seok et al., 2013). Nordin and Glimelius (1998) assessing GI cancer patients suggested that 'fighting spirit' is related to better emotional well-being while helpless/hopeless and anxious preoccupation strategies have a reverse effect. Similarly, a previous cross-sectional study on 30 American prostate cancer patients confirms that a higher score of 'helplessness/hopelessness' is related to lower self-esteem, and higher 'anxious preoccupation' is related to higher depression. Optimism was suggested as a negative factor for both anxiety and depression (Bjorck, Hopp, & Jones, 1999). Schnoll, Harlow, Brandt, and Stolbach (1998) examined the relationship between mental attitude and emotional adjustment in 58 American cancer patients. They outlined that 'fighting spirit' is related to better emotional adjustment while 'hopeless/helpless' and 'anxious preoccupation' have an opposite effect.

Patients with low 'fighting spirit', high 'helplessness/hopelessness' and moderate 'anxious preoccupation' reported high levels of emotional distress. Low 'hopelessness/helplessness', high 'positive reappraisal', 'high positive attitude' and high 'vigilant participation' predicted lower levels of emotional distress. In Canada, Hack and Degner (2004) demonstrated that breast cancer patients who respond to their diagnosis with 'passive acceptance' and 'resignation' are at significant risk of poor psychological adjustment three years later. Moreover, poor adjustment was shown to be related to 'cognitive avoidance' and minimal use of approach-based coping responses. Another cross-sectional study in the US assessing coping strategies associated with psychological adjustment to advanced breast cancer found no association between mood disturbance and 'denial' or 'fatalism'. However, 'fighting spirit' and 'emotional expressiveness' were found to be predictors of better adjustment (Classen, Koopman, Angell, & Spiegel, 1996). Due to all these results, the quantitative studies have not shown a clear role for adjustment such as 'fatalism' and 'cognitive avoidance'. We found two qualitative studies describing the adjustment 'fatalism'. Through a qualitative approach exploring strategies for coping with cancer among 39 Iranian breast cancer survivors, the force of spirituality to accept the disease that can be cured was described. Participants related their cancer to the will of God, which they cannot change because it is part of their faith. Being preoccupied with both individual and group activities to distract from thinking about cancer was another reported common strategy. The fatalistic view was reported as a facilitator for medical follow-up and treatment engagement (Harandy et al., 2009). Similarly, Cheng, Sit, Twinn, Cheng, and Thorne (2013) conducted in-depth interviews with 29 Chinese cancer patients to explore the role of 'fatalism' in coping with cancer. Using content analysis, the results showed that participants believed in 'fatalism' and accepted their inability to change the final outcome of cancer. They stated fatalistic beliefs, their acceptance of the way things are and the exertion of personal efforts over the situation. The concept of 'fatalistic voluntarism' was introduced in this study. Similar to Harandy et al. (2009), this study concluded that a fatalistic view has a positive influence on managing the challenges of cancer.

Further studies employing more in-depth qualitative approaches are needed to explore the role of each mental adjustment category especially in different cultural contexts. There is also a gap in knowledge around optimal mental adjustment among cancer patients and how this differs between cancer survivors.

## **Impacts**

Psychological responses and mental adjustment to cancer have been suggested to influence many health-related factors including psychological and emotional morbidity, survival, mood disturbances and quality of life (Cordova et al., 2003; Ferrero et al., 1994; Ganz et al., 2003; Grassi et al., 2004; Johansson et al., 2011; Schou, Ekeberg, Ruland, Sandvik, & Kåresen, 2004; Watson et al., 1991; Watson et al., 1999; Watson, Homewood, & Haviland, 2012; Watson, Homewood, Haviland, & Bliss, 2005).

The possible impacts of psychological responses on the outcome of the disease have been investigated as the literature often shows. A 5 year prospective study in London on early breast cancer patients showed that recurrence-free survival is common among patients who have initially reacted to cancer by 'denial' or 'fighting spirit' compared to who have responded with 'stoic acceptance' or feeling of 'helplessness/hopelessness' (Greer et al., 1979). Watson et al. (2005) in a 10 year follow up study indicated that there is a continuing effect of 'helplessness/hopelessness' on disease-free survival but not of depression. 'Fighting spirit' did not show any survival advantage. The baseline 'helpless/hopeless' response has a significant effect on survival for up to 10 years. Johansson et al. (2011) confirmed that using a helpless/hopeless response is related to poorer survival. Watson et al. (2012) studied impacts of coping response on survival of breast cancer over 5 years. The results showed that prior 'negative adjustment' was linked to increased risk of death and relapse of breast cancer for up to 10 years. There were no 'positive adjustment' effects on survival.

A number of studies indicated that psychological adjustment impacts on psychological morbidity. Watson et al. (1991) showed a significant association between controlling emotional reactions and 'fatalism', and between anger control and a helpless attitude. A 5 year prospective study on 578 women with early-stage breast cancer reported a significant increased risk of death in women with high scores of 'anxiety/depression' and 'helplessness'; however, there were no significant results for 'fighting spirit' (Watson et al., 1999). Similarly, Grassi et al. (2004) stated that 'hopelessness' and 'anxious preoccupation' are the most significant coping styles correlated with psychosocial morbidity; however, the role of 'fighting spirit' is not significant. Nosarti, Roberts, Crayford, McKenzie, and David (2002) stated the pre-diagnostic general health, lack of social support, feeling of personal responsibility and avoidance predict psychological morbidity. Cordova et al. (2003) have indicated that lower emotional suppression and greater levels of 'fighting spirit' are associated with lower mood disturbance. Schnoll, Mackinnon, Stolbach, and Lorman (2007) examined the relationship between mental

attitude and emotional adjustment. They concluded that ‘fighting spirit’ is linked to better emotional adjustment, whereas ‘hopelessness/helplessness’ and ‘anxious preoccupation’ are linked to poor emotional adjustment and high levels of emotional distress.

The literature has pointed out the impacts of mental adjustment on quality of life for cancer patients. Ferrero et al. (1994) suggested that ‘fighting spirit’ and ‘denial’ are associated with better present and future quality of life, whereas ‘helplessness/hopelessness’, ‘anxious preoccupation’ and ‘fatalism’ responses are negatively associated with well-being. Comparably, Ganz et al. (2003) stated that better physical and mental health as well as better emotional social support predicts more self-perceived health. In a similar way, Johansson et al. (2011), using a 12 month longitudinal design in Sweden, investigated the relationship between mental adjustment to cancer and health related quality of life among 95 laryngeal cancer patients. They concluded that patients using ‘helpless/hopeless’ and ‘anxious preoccupation’ experience more anxiety and depression as well as decreased health-related quality of life.

Mental adjustment may impact on cancer patients’ information needs. In a cross-sectional study of 73 Australian lung cancer patients, the high levels of the ‘fighting spirit’ and ‘anxious preoccupation’ were shown to be associated with a high need for disease oriented information, whereas ‘cognitive avoidance’ was associated with low information needs. High levels of ‘anxious preoccupation’ were reported to be positively related to high levels of action-oriented information needs as well (Mulcare et al., 2011).

Although the impacts of mental adjustment to cancer on many health-related factors have been well shown by literature, additional research may help develop an improved and greater understanding.

### **Predictors**

The diagnosis of cancer is highly related to changes in psychological functioning comparing to other health-related diagnoses (Polsky et al., 2005). Previous studies suggested that patients’ characteristics, baseline health, performance status, stage of disease and cancer treatments are associated with the cancer adjustment (Akechi et al., 2000; Akechi, Kugaya, et al., 1998; Akechi, Okamura, Yamawaki, & Uchitomi, 1998; Bellardita et al., 2013; Burton, Galatzer-Levy, & Bonanno, 2015; Hulbert-Williams et al., 2012; Inoue, Saeki, Mantani, Okamura, & Yamawaki, 2003; Okano et al., 2001; Schlegel, Manning, Molix, Talley, & Bettencourt, 2012; Schnoll et al., 1998). Other studies have revealed that personality variables (e.g. coping styles) are important factors in psychological adjustment (Bloom, 1982; Cicero et al., 2009; Groarke,

Curtis, & Kerin, 2013; Heim et al., 1997; Schnoll et al., 1998). Then again, several studies indicated that high levels of perceived social support are associated with better adjustment to cancer (Akechi, Okamura, et al., 1998; Bloom, 1982; Cicero et al., 2009; Eom et al., 2013; Grassi, Rosti, Lasalvia, & Marangolo, 1993; Helgeson et al., 2004; Inoue et al., 2003; Schnoll et al., 1998). Religious/spiritual coping have been assessed for adjustment to cancer as well (Exline, Park, Smyth, & Carey, 2011; Thune-Boyle, Stygall, Keshtgar, & Newman, 2006).

An individual's appraisal of stressors in relation to a given situation is the strongest and most consistent predictor of adjustment (Groarke et al., 2013). They assessed a total of 241 Italian women with a first diagnosis of breast cancer who were awaiting surgery, and then 4 months later. Post-surgery results demonstrated that cancer-related stress predicts only negative affective outcomes. The coping strategies were known as less powerful predictors of emotional adjustment. In the UK, Hulbert-Williams et al. (2012) found that earlier levels of anxiety are accounted as one of the most important predictors of cancer adjustment over time. Patients with high levels of anxious attachment showed coping styles like 'helplessness/hopelessness' and 'anxious occupation' which predict psychological adjustment (Cicero et al., 2009). The coping strategies, such as support and self-control, and to a lesser degree denial and diverting that can be generally categorized as good forms, are associated with psychological adaptation. Conversely, poor coping styles have a negative effect on most criteria of adjustment (Heim et al., 1997). Schnoll et al. (1998) reported coping styles as an essential mediating factor for psychological adaptation. In a study of 87 ambulatory Japanese lung cancer patients, coping style of 'helplessness/hopelessness' was reported as a predictor of psychological distress (Akechi, Okamura, et al., 1998). 'Fighting spirit' coping is related to low external locus of control, while an opposite association was reported for 'helplessness/hopelessness' and 'fatalism' (Grassi et al., 1993). Akechi, Okamura, et al. (1998) investigated whether cancer patients' characteristics predict two types of mental adjustment (fighting spirit and helplessness/hopelessness). A total of 455 ambulatory Japanese cancer patients completed the Mental Adjustment to Cancer (MAC) scale and participated in a structured interview. Household size, performance status, confidence (physicians) and satisfaction with confidants were reported as predictive of 'fighting spirit'. Age, education, household size, performance status and satisfaction with confidants were shown as predictive of 'helplessness/hopelessness'. Although living with others was associated with 'fighting spirit', marital status was not. Among all the medical variables, performance status was the only predictors of 'fighting spirit' which affects patients' perception of stress. The cancer patients

with poorer performance status reported more difficult coping with disease. Only physicians were considered to be one of the most effective sources of social support, which is related to 'fighting spirit'.

Another study examining factors correlated with mental adjustment of 'fighting spirit' and 'helplessness/hopelessness' in breast cancer patients showed that the performance status and history of major depression were correlated to 'fighting spirit', while age, pain and history of major depression were correlated with 'helplessness/hopelessness' significantly (Okano et al., 2001). A cross-sectional study on breast cancer patients coping responses to the diagnosis of cancer illustrated a correlation between high levels of education with low 'fighting spirit' score on the Mental Adjustment to Cancer (MAC) scale (Inoue et al., 2003). Cancer treatments, depressive symptom changes, baseline health and age have been shown to be important in long-term patterns of psychological adjustment (Burton et al., 2015). In a study of 100 American women diagnosed with breast cancer, Schnoll et al. (1998) revealed that age and stage of disease are not directly associated with psychological adjustment and are mediated by coping styles. Younger breast cancer patients and women with an earlier disease stage used coping styles like 'fighting spirit' more, and 'helplessness/hopelessness', 'anxious preoccupation' and 'fatalism' less. Coping styles were introduced as an essential mediating factor for psychological adaptation.

Schlegel et al. (2012), in a large prospective study on 250 American breast cancer patients, showed that women who were not married, had children at home, had to travel long distances to receive treatment and had lower income, reported higher levels of depressive symptoms. Younger women reported more depressive symptoms during initial treatment, but this effect dissipated after the completion of treatment. Another study on 107 Japanese patients with head and neck cancer showed that having an advanced stage of cancer and living alone were significantly associated with psychological distress (Akechi, Kugaya, et al., 1998).

The above studies demonstrate that there is a variety of personal, environmental and behavioural factors that predict and interpret mental adjustment to cancer, but the lack of an underpinning theory in these studies is evident. The theoretical framework helps to make research findings meaningful and interpretable, and explain "what" and "why" they occur (Polit & Beck, 2013).

## **Mental adjustment changes over time**

Adjustment is a change from one state to another; however, research has mostly focused at the end point rather than the process of change (Brennan, 2001). Many studies have described the initial adjustment period while fewer studies have examined the long term patterns of adjustment. A longitudinal study assessed the trajectories of adjustment on 363 women diagnosed with stage I, II and III breast cancer over 4 years in the US. Four distinct trajectories were found in this study. The largest percentage of participants (43%) showed the highest levels of mental functioning which was fairly steady throughout this study. The other two trajectories started out with a low level of mental functioning one of which immediately improved over time with some deterioration toward the end of the study; however, the other showed an immediate decline which improved toward the end of the study. The physical functioning was shown to be strongly related to mental functioning other than vice versa. Demographic variables and disease variables had very little effects on these trajectories with the exception of age. The group with the lowest level of physical functioning that reported deterioration over time was the oldest. Personal and social resources were the best predictor of trajectories of mental and physical functioning (Helgeson et al., 2004).

Some studies described a fairly stable adjustment response over time as well. In Sweden, a longitudinal design on 95 patients with laryngeal cancer found that the use of adjustment responses was relatively stable over time. The 'fighting spirit' was the most commonly used adjustment response at one and 12 months after start of treatment. The 'helpless/hopeless' and 'anxious preoccupation' were related to more anxiety and depression (Johansson et al., 2011). Before that, Nordin and Glimelius (1998) had confirmed that there were only minor changes of emotional well-being and coping strategies among 139 newly diagnosed GI cancer patients in Sweden over time. They believed that the way coping strategies and emotional well-being change over time is not simple. Similarly in Switzerland, Heim et al. (1997) found that psychosocial adjustment among 74 breast cancer patients was fairly stable over a 3 to 5 year period. They showed a positive relationship between psychosocial adaptation and good forms of coping, such as support and self-control, and less for diverting and denial.

Some longitudinal studies have shown a decline in psychosocial adjustment over time. In the US, Ganz et al. (2003) assessed breast cancer women aged 65 years and older, 3 months after surgery and at two additional times in the following years. They reported a significant decline in physical and mental health scores in the follow up year. Similarly, better mental health,

emotional social support and better interaction with health care providers predicted a better psychosocial adjustment. Another study assessed a consecutive series of 87 patients aged 45-75 years prior to diagnosis of breast cancer, and 8 weeks and 9 months after first follow-up in the UK. The coping response scores were lower at both post-diagnostic assessments compared to the first follow-up. However, it was only significant for three responses: 'fighting spirit', 'stoic acceptance' and 'anxious preoccupation' (Nosarti et al., 2002). Couper et al. (2010) suggested the pattern of change for distress in cancer. They assessed psychosocial distress in Australian patients with early and advanced prostate cancer patients at diagnosis and 12 months later. Both early and advanced prostate cancer patients reported reduced vitality and increased depression and anxiety 12 months later; this was greater in the advanced group. 'Fatalism' coping pattern and vitality at time 1 predicted depression at time 2 for the early group. Anxiety at time 2 was related to anxiety and vitality at time 1. This study confirmed an increasing psychosocial distress in early prostate cancer patients over the 12 months following the diagnosis.

Carver et al. (1993) conducted a series of interviews with 59 newly diagnosed American breast cancer patients before surgery, 7-10 days after surgery and at 3, 6 and 12 months follow-up. Patients did not report an extreme distress at any point of the study. Mood disturbance was the highest before the surgery and it decreased after surgery. Active coping fell from before surgery to the 3 months after surgery. Most of the coping reactions were more prominent at first than later. Some of the responses, such as planning and use of religion, fell off quickly after surgery or by 3 months post-surgery. Some responses showed a gradual decrease over time. Acceptance was reported as a different pattern, which drifted upward across the time although it was marginally significant. The patients reported acceptance, positive reframing and use of religion as the most common reactions, whereas denial and behavioural disengagement were the least. Acceptance and use of humour were related to less distress prospectively.

One study showed an improvement in mental adjustment over time. In Italy, Grassi and Rosti (1996) studied psychiatric morbidity and adjustment to illness in 52 cancer patients for 6 years prospectively. They reported that the prevalence of psychiatric disorders decreased from 47% to 37%. There was an improvement in psychological adjustment between two assessment points. The external locus of control, low social support, abnormal illness behaviour, emotional stress and poor coping mechanisms at first assessment predicted psychological symptoms and maladjustment to cancer at second assessment. Table 1.1 summarizes some literature about changes of coping responses and mental adjustment to cancer over time.

**Table 2.1: Longitudinal studies tracking changes of coping responses and mental adjustment to cancer over time**

Reference	Samples	country	Period of time	Findings	changes
<b>Helgeson et al. (2004)</b>	Breast cancer	USA	4 years	43% reported a fairly steady trajectory	<b>Stable</b>
<b>Johansson et al. (2011)</b>	Laryngeal cancer	Sweden	12 months	Using of adjustment responses was stable over time	
<b>Nordin and Glimelius (1998)</b>	GI cancer	Sweden	12 months	Minor changes of emotional well-being and coping strategies over time	
<b>Heim et al. (1997)</b>	Breast cancer	Switzerland	3-5 years	Fairly stable psychological adjustment	
<b>Ganz et al. (2003)</b>	Breast cancer	USA	12 months	Significant decline in physical and mental health scores in the follow-up year	<b>Decline</b>
<b>Nosarti et al. (2002)</b>	Breast cancer	UK	9 months	Coping response scores were lower at both follow-up	
<b>Couper et al. (2010)</b>	Prostate cancer	Australia	12 months	Reduced vitality and increased depression and anxiety were reported 12 months later	
<b>Carver et al. (1993)</b>	Breast cancer	USA	12 months	Mood disturbances decreased and coping responses decreased over time excepting acceptance	<b>Improved</b>
<b>Grassi et al. (2005)</b>	Long term cancer survivors	Italy	6 years	Psychiatric disorders decreased over time. Psychological adjustment improved.	

There is limited agreement on how mental adjustment to cancer changes over time. There is a need for more longitudinal research at multiple time points, particularly at diagnosis and the theory-guided, qualitative approaches may illustrate more details around new patterns of mental adjustment to cancer changes over time.

## **Bandura's Socio-cognitive theory**

The socio-cognitive theory has been employed to enhance health behaviours and adjustment to chronic illnesses (Bandura, 1997). The dynamic and reciprocal model of interactions among behaviour, person and environment explains the SCT, and self-efficacy is the key construct of this theory (Bandura, 2002).

Many theories have explained the impact of cognitive and social factors on human health and disease; and Bandura's SCT is one of them. The SCT explains the factors which profoundly affect physical and emotional well-being as well as the self-regulation of health habits. Knowledge is necessary but not enough to adopt a new style habit. Personal efficacy has a pivotal regulative role in SCT. Besides skills, a strong sense of efficacy is needed to use them effectively and consistently. Self-efficacy predicts how much stress and depression will be experienced in coping with taxing environmental demands. In contrast, inefficacy to control over threats explains stress reactions. Outcome-expectations and self-regulation of habits also contribute to health behaviour in SCT (Bandura, 1998).

The impact of self-efficacy is well known in the field of psycho-oncology. Outcome expectations and self-regulation are the other two components of SCT which may predict cancer patients' quality of life and adjustment (Graves, Carter, Anderson, & Winett, 2003).

Rogers et al. (2005) suggested that SCT can be used as a framework to assess physical activity in breast cancer patients during treatment. They showed a significant association between higher daily energy expenditure with higher self-efficacy barrier. Graves (2003) describes SCT as a treatment framework to assess quality of life through intervention with cancer patients. They suggested that the mechanism of changes of interventions based on SCT can be evaluated through SCT's components: self-efficacy, outcome expectations and self-regulation. In this meta-analysis study, the SCT-based interventions were introduced to be associated with quality of life outcome; however, it was suggested that there was no relationship between the SCT's components of anxiety, coping and physical outcomes. Graves et al. (2003) conducted a pilot, randomized project on American breast cancer patients to compare the impact of SCT-based skill-building with standard-care on quality of life. The intervention group reported higher outcome-expectations, but the impact on quality of life was not supported. The intervention group reported some skills such as changing negative thoughts, clear communication about cancer, using relaxation techniques and setting goals.

The social-cognitive theory explains that human's behavior is the result of reciprocal and dynamic interplay of (a) personal factors (e.g. cognition, affect), (b) behavior and (c) environmental influences (Bandura, 2011). The behavioral change can be evaluated based on the factors: the environment, people and behavior. These three factors are constantly influencing each other (Glanz, Rimer, Lewis, & Jossey-Bass, 2002). The SCT can be an effective framework in increasing and even maintaining positive health behavior. The three components of the SCT – self-efficacy, outcome expectations and self-regulation – are the predictors of positive changes in psycho-oncology. The positive change for cancer patients is improved quality of life (Graves, 2003).

### **Self-efficacy**

Self-efficacy can be defined as a form of cognitive appraisal which is important in predicting adjustment and well-being.

Bandura's SCT describes it as follows:

*Perceived self-efficacy refers to beliefs in one's capabilities to organize and execute the courses of action required to produce given attainments (Bandura, 1997, p.159).*

It shows the confidence individuals have in their ability to perform a task or behaviour and is a core component of SCT. According to Bandura's theory, newly diagnosed cancer patients perceive their disease as a threat and may or may not react depending on their efficacy beliefs. Self-efficacy changes the situation from threatening to safe through to decreasing anxiety. General self-efficacy is a relatively stable generalized belief that an individual can use the resources to deal with challenges. It explains a variety set of adherence behaviours or the perception of health or various symptoms. Patients' ability to manage the physical and psychological challenges of cancer can be managed through self-efficacy beliefs (Bandura, 1997). Studies on patients' adjustment to cancer have examined self-efficacy as one of the impacting factors. Patients with a high sense of coping efficacy try to change hazardous environments into more benign ones (Bandura, 1986). Social-cognitive theory believes that self-efficacy strongly influences behaviour and is positively related to adjustment (Bandura, 1997).

Older age, less time since diagnosis, and less distress predict greater self-efficacy for coping with cancer (Mosher, DuHamel, Egert, & Smith, 2010). There is a relationship between poorer financial status and fatigue with lower self-efficacy (Haas, 2011). Mystakidou et al. (2010)

found that patients' age, performance status, gender and high levels of anxiety predicted self-efficacy in 99 cancer patients in a palliative care unit in Greece. Another study on 148 Chinese gastric and colorectal cancer patients showed that less depression, better physical function, more social support and higher vitality predict higher levels of self-care self-efficacy and depression had the largest impact (Qian & Yuan, 2012). Similarly in Denmark, Nielsen, Mehlsen, Jensen, and Zachariae (2013) reported that depressive symptoms are the strongest predictor for both coping and decision self-efficacy. In this study, marital status was a significant predictor for coping self-efficacy and satisfaction with information led to better decision self-efficacy. The patients' ratings of physician-patient relationship did not show a significant association.

Coping self-efficacy is an important predictor of patients' adjustment. It is not only a significant predictor of depression, it is also a mediator between symptoms and depression (Philip, Merluzzi, Zhang, & Heitzmann, 2013). Higher depression and fatigue are predicted by lower self-efficacy coping with cancer (Albrecht et al., 2013).

A study on the influence of self-efficacy on symptom distress among 252 Chinese colorectal cancer patients receiving post-operative adjuvant chemotherapy found that greater self-efficacy was related to milder symptom severity and less symptom interference with daily life (Zhang et al., 2015). In the US, Shelby et al. (2014) confirmed that self-efficacy for coping with symptoms reduce the negative impact of physical symptoms. They assessed 112 women who were taking adjuvant endocrine therapy for breast cancer and reported that higher self-efficacy for coping with symptoms is related to better functional, emotional and social well-being. A large perspective study among 1527 breast American cancer survivors revealed that physical activity indirectly influenced fatigue via self-efficacy and depression which was supported across time (Phillips & McAuley, 2013).

Bains et al. (2012) explored the impact of self-efficacy on 50 colorectal cancer patients' work ability and employment outcomes in UK prospectively. Results reported that job self-efficacy was related to work ability at 3 and 6 months later. In Germany, another study on 118 breast cancer patients revealed that high levels of fear of disease progression was significantly associated with low self-efficacy (Melchior et al., 2013). In a longitudinal study in Greece, Mystakidou et al. (2013) investigated changes of general self-efficacy among 90 cancer patients. The general self-efficacy was reduced at post-treatment and higher general self-efficacy was related to higher anxiety and symptom severity but a better quality of life. In the

US, Yeung and Lu (2014) confirmed that self-efficacy is positively associated with quality of life and positive affect. Similarly, in a study among 47 Japanese gastrointestinal cancer survivors a positive correlation between self-efficacy and quality of life was well recognized (Kohno et al., 2010).

Self-efficacy is a cognitive variable for adjustment to cancer. Beckham, Burker, Lytle, Feldman, and Costakis (1997) assessed 52 cancer patients to explore the relationship between self-efficacy and cancer adjustment in the US. They confirmed that the relationship between patient self-efficacy, and cancer adjustment and psychological distress is significant even when age, education and current disease status were controlled. Lev, Paul, and Owen (1999) studied self-care self-efficacy and adjustment among 307 American cancer patients at all stages of cancer at baseline, 4 months and 6 months later. The results revealed that there is a significant decrease in patients' self-care, self-efficacy and quality of life over time, but measures of patients' symptoms and mood disturbances did not change. The greatest decrease for the self-care, self-efficacy and quality of life occurred between baseline and 4 months. Self-efficacy and adjustment were associated with high coping and enjoying life.

Rottmann, Dalton, Christensen, Frederiksen, and Johansen (2010) investigated self-efficacy and mental adjustment among 684 breast cancer patients in Denmark. Participants completed self-efficacy scale and Mini-MAC at baseline, 1 month and 12 months later. The result showed that self-efficacy at baseline was related to emotional well-being 12 months later. Better self-efficacy predicted more active, approach-oriented adjustment style (more fighting spirit, and less anxious preoccupation and hopelessness/helplessness). The relationship with emotional well-being decreased but it was still significant when mental adjustment at 1 month follow-up was concerned. They concluded that self-efficacy is a personal resource that predicts long term adaptation and employing adaptive styles.

### **Self-regulation**

Self-regulation systems help adapting to threats via coping strategies (Leventhal, Leventhal, & Contrada, 1998). Maddux (1995) describes it as follows:

*People are capable of self-regulation by influencing direct control over their own behaviour and by selecting or altering environmental conditions that, in turn, influence their behaviour. People adopt personal standards for their behaviour; evaluate their behaviour against these standards (p.5).*

Self-regulation is one of the SCT constructs which explains human agency and the influence of personal factors on behaviour and the environment (Denler, Wolters, & Benzon, 2014). The active process of self-regulation may help positive adjustment among cancer patients, because avoidant coping strategies have been shown to result in poorer outcomes (Stanton & Snider, 1993).

The term self-regulation has been defined as an aspect of control theories and it has been studied related to coping with symptoms or medical treatments (Grossarth-Maticek & Eysenck, 1995). It has been shown that patients who are able to disengage from unattainable goals, set alternative goals and regulate their emotions would experience less negative and more positive affect (Schroevers, Kraaij, & Garnefski, 2008).

The concept of emotion regulation is defined as follows:

*All extrinsic and intrinsic processes responsible for monitoring, evaluating and modifying emotional reactions". These processes are important in supporting adaptive and organized behavioural strategies (Thompson, 1994, p.27-28).*

According to the definition of coping by Lazarus (1991), all coping efforts come under the definition of emotion regulation (Garnefski, Kraaij, & Spinhoven, 2001). The cognitive emotion regulation questionnaire (CERQ), which was designed by N Garnefski et al. (2001), measures nine cognitive coping strategies people may take after negative life events. Cognitive emotion regulation is a mediator between negative life events and depression/anxiety. Different cognitive coping strategies include: self-blame, other blame, rumination, catastrophizing, acceptance, putting into perspectives, positive refocus on planning and positive reappraisal. It has been shown that self-blame, rumination, catastrophizing and positive reappraisal are valuable predictors of negative emotions (Martin & Dahlen, 2005).

People are different in choosing emotion regulation strategies. It is confirmed that reappraisal is related positively to well-being while suppression strategies are related negatively (Gross & John, 2003). N. Garnefski, Van Den Kommer, et al. (2002) compared using cognitive emotion regulation strategies between clinical and non-clinical adults in Netherland. The results revealed that self-blame and catastrophizing were more common in the clinical group.

Cognitive emotion regulation strategies play an important role in psychopathology. The adaptive strategies (i.e. reappraisal and problem-solving) is less important in cognitive emotion

regulation compared to maladaptive strategies (Aldao & Nolen-Hoeksema, 2010). N. Garnefski and Kraaij (2006b) compared using cognitive emotion regulation in different age groups. They found that there was a remarkable difference in strategies used by groups, but the relationship between cognitive regulation strategies and depression was similar.

The major aim of emotion regulation is modifying emotional responses. People may choose from a variety of emotional regulatory responses to reach the best benefit in a particular situation (Gross, 2002).

The literature confirms that the self-regulatory skills help individuals to anticipate, avoid and minimize the stressful events and the basic process of self-regulation with social interactions, and exceptional coping strategies come together to be called as the proactive coping (Aspinwall & Taylor, 1997). To our knowledge, there are no studies about the role of self-regulatory behaviours in mental adjustment to cancer, but some studies have shown a predictive role of self-regulation for coping in other situations (Lengua & Long, 2002). It seems that the value of self-regulation in mental adjustment to cancer has been underestimated and it requires more consideration.

### **Outcome expectations**

The outcome expectations are defined as follows:

*“The physical, social and self-evaluative expectations one held for the outcome of behaviour”. It is defined as “the subjective probability that a particular behaviour will be followed by a particular outcome (Kirsch, 1995, p. 333).*

People’s expectations about the outcome of their actions influence the consequences of those actions. While they see desired outcomes as attainable, they continue to acquire those outcomes (Scheier & Carver, 1992).

Cancer patients assess their cancer experience, which is influenced by positive or negative expectations. Outcome expectations may be used to assess patients’ expectations of coping behaviours. Measurement of outcome expectations may identify patients with negative expectations which limit using effective coping strategies and ability to adapt to illness (Graves & Carter, 2005).

Scheier and Carver (1992) suggested the Life Orientation Test (LOT) to measure outcome expectations. It consists of half optimistic phrases and half pessimistic ones. Optimists view

the best face of a situation and accept the reality of problems instead of wishing them away. They are active and constructive to make the situation better. Pessimists tend to pick tactics of avoiding coping and they are more likely to give up. Psychiatric morbidity is less common in cancer patients who are unaware of the diagnosis and who consider treatment as curative (Alexander, Dinesh, & Vidyasagar, 1993). The predictive factors for emotional morbidity were examined in a study of 165 newly diagnosed breast cancer women one year following surgery with special focus on dispositional optimism/pessimism in Norway. Pessimism was the most important predictor for anxiety one year following breast cancer surgery. Optimists who were experiencing more anxiety at diagnosis time reported 6 times higher risk of anxiety after one year, compared to optimists without anxiety before the surgery. The more pessimistic a person was, the higher the risk for developing anxiety one year after surgery. Pessimists with a helpless/hopeless coping style showed three times greater risk for experiencing depression one year after surgery (Schou et al., 2004).

When cancer patients are optimistic about the treatment; they may have better psychological adjustment even if the expectations are unrealistic. The expression of negative affects and attitudes of realistic optimism may improve adjustment and reduce distress (Cordova et al., 2003). A study among Americans suffering from metastatic renal cell carcinoma and melanoma showed that patients who believed that treatment would cure them and stop the progression reported fewer symptoms of depression, lower mood disturbance and fewer symptoms of distress (Cohen, de Moor, & Amato, 2001). Similarly, Marks, Richardson, Graham, and Levine (1986) confirmed a strong negative relationship between treatment expectations and depression in newly diagnosed American cancer patients who perceived their illness as very severe. On the other hand, Wan, Counte, and Cella (1997) explained that the gap between expectations and actual experiences should be narrowed to enhance quality of life. Therefore, patients may benefit more if they set and maintain realistic goals about their cancer prognosis and treatment consequences. Conversely, Koller et al. (2000) stated that expectation of healing improves quality of life and healing after radiotherapy in cancer patients.

In social cognitive theory, outcome expectations about the effects of different life style habits result in health behaviour, and positive expectations act as incentives for them (Bandura, 1998). It seems that the outcome expectations deserve additional studies especially in relationship to adjustment to cancer.

## **Social support**

The SCT suggests that learning and behavior (cognition) have a reciprocal relationship with the environment (Bandura, 2001). Bandura (1998) describes that human agency interacts with a broad social network and many health behaviors are related to people's social lives. The environment refers to the factors which can affect the behavior. There are the social and physical environments; the social environment can be described as family members, friends and colleagues. The environment and the situation can help to understand the behavior and it's comprised of the situation, roles, models and relationships. The three factors environment, people and behavior are constantly influencing each other. Behavior is not simply the result of the environment and the person, just as the environment is not simply the result of the person and behavior (Glanz et al., 2002).

In several studies, social support has been identified as an important predictor of psychosocial distress for cancer patients. Social support has been described as interpersonal relationships that protect people from the deleterious effects of stress (Wortman, 1984). Several studies investigated the impacts of social support on mental adjustment to cancer. In a cross sectional study in Italy, Cicero et al. (2009) demonstrated that perceived social support from friends may predict the patient's tendency to consider cancer as a challenge and to take an active role in therapy and recovery, while social support from family does not predict various states of adjustment to cancer. However, living alone has been shown to be associated with psychological distress among cancer patients (Kugaya et al., 2000). Along the same lines, Inoue et al. (2003) reported that poor family functioning is correlated with high 'hopelessness/helplessness'. Similarly, Schlegel et al. (2012) illustrated that breast cancer women who were not married but have children living at home may report higher levels of depressive symptoms. Akechi, Kugaya, et al. (1998) stated that support from physician and satisfaction with support may predict 'fighting spirit' and 'helplessness/hopelessness'. In a recent large cross sectional study in Korea, Eom et al. (2013) studied the impact of perceived social support on the mental health and health-related quality of life in among 1930 cancer patients and reported that low perceived social support is significantly associated with higher levels of depression and lower global health/quality of life. Nosarti et al. (2002) illustrated that the presence of social support may be associated with successful adjustment in the first year following a breast cancer diagnosis. Social support may help distinguish different courses of mental and physical functioning (Helgeson et al., 2004). Some literature has investigated different indicators of social support. Bloom (1982) stated that perception of family

cohesiveness and the amount of social contact have direct effects on coping and indirect effects on adjustment. Overall, social support is associated with mental adjustment in cancer patients and more investigations might be helpful for improving the interventions to enhance mental health and quality of life.

## **Conclusion**

This review has presented an overview of what people may experience after receiving a diagnosis of cancer. Cancer can be perceived as a threat which may cause distress and psychiatric symptoms such as depression and anxiety. Mental adjustment to cancer includes involuntary emotional reactions to this threat and what people think and do to control the diagnosis of cancer. This has been well defined and categorized by many studies. Patients' characteristics, health and disease status, personality variables, social support and spirituality have been introduced as predictors of mental adjustment to cancer by the literature. Studies have suggested that psychological responses to a diagnosis of cancer impacts on psychological and emotional morbidity and survival which ultimately affect quality of life.

Many studies have assessed the initial period of adjustment but fewer studies have followed it up for long term periods. Stable and declining patterns of change over time in adjustment to diagnosis of cancer have been reported by most longitudinal quantitative studies; however, there are very few in-depth qualitative follow-up designs. Using qualitative analysis may help to explain how cancer patients accept and react to this situation.

Theories have been described that both cognitive and social factors impact on health behaviours and adjustment to chronic illness, and Bandura's SCT is one of them. This theory predicts cancer patients' adjustment and quality of life through the three components of self-efficacy, outcome expectations and self-regulation. The impact of self-efficacy has been well reported in oncology; however, it seems that the value of outcome expectations and self-regulation deserve additional study especially in relationship to adjustment to the diagnosis of cancer.

This review did not find any study conducted in New Zealand to explain how New Zealanders learn to live and adjust to a diagnosis of cancer. According to statistics, colorectal cancer is the most common cancer in New Zealand and living with cancer would be a challenge. This thesis examines mental adjustment to colon cancer after diagnosis and over a 4-6 month period. Using a mixed methods design and a socio-cognitive theory lens, the study sought to gain better understanding of mental adjustment to cancer over time in the New Zealand context.

# Chapter Three

## Methodology and Methods

### Introduction

This chapter sets out the methodology and the methods used in this thesis. An overview of pragmatism will be set out with its relevance to mixed methods research. Mixed methods research will be introduced including key researchers and its strengths and limitations of the approach before focusing on Creswell's (2011) convergent parallel mixed methods research design. The theoretical framework underpinning the study is a socio-cognitive approach to explore mental adjustment to the diagnosis of colon cancer diagnosis, therefore the concepts of socio-cognitive theory are outlined. The research methods will describe the process employed in conducting the study.

### Methodology

Methodology (methods, approach and technique) are employed in every research which helps the study to move from the beginning to the end (Minichiello, Sullivan, Greenwood, & Axford, 2004). Three basic components in every research enterprise: the subject of the research, the object of the research and the context of the research. The conceptualisation process defines the actual research topic and reveals the sub-concepts which underpin the main study (Taylor, Kermode, & Roberts, 2006).

### Research design

Crotty (1998) suggests that four questions in designing a research proposal should be asked:

**-Epistemology:** what is the theory of knowledge embedded in the theoretical perspective (e.g., objectivism, subjectivism)

**-Theoretical perspective:** what is the philosophical stance lays behinds the methodology in questions (e.g., positivism and post positivism, interpretivism, critical theory, etc.)

**-Methodology:** what is the strategy of action that links methods to outcomes (e.g. experimental research, survey research, ethnography, etc.)

**-Methods:** what techniques and procedures are proposed to use (e.g., questionnaires, interview, focus group, etc.)

These four questions describe the levels of deciding about the research design. Moreover, in this approach, it is easy to move from the assumptions toward the practical decisions about data collection and analysis (Creswell, 2003).

Based on Crotty's model, Creswell (2003) suggests three questions central to the design of research:

What knowledge claims are being described (theoretical perspective)?

What strategies will be used?

What methods of data collection and analysis will be employed?

The first step of designing a research proposal is assessment of the all knowledge claims of the study to find out which strategy is the best to be used. Then, the specific methods can be identified (Creswell, 2003). The researcher starts a study with a certain assumption. There are four schools of thought about these claims: post-positivism, constructivism, advocacy/participatory and pragmatism (Creswell, 2003). Creswell (2003) describes that the post-positivists assume a traditional form of research which holds true more for quantitative research than qualitative research. This view is sometimes called the scientific method or a science research. It is also called post-positivism because it represents the thinking after positivism, challenging the traditional notion of the absolute truth of knowledge. For the **post-positivists**, reality may be known and casual linkage may be claimed. They employ deductive logic and quantitative methods of research. Post-positivists support the philosophy in which causes effects or outcomes. They try to assess the causes that influences outcomes, such as found in experiments. It intends to reduce the ideas into a small, discrete set of ideas to test, such as the variables that comprise hypotheses and research questions. It is also based on careful observation and measurement of the objective reality that exists 'out there' in the world. Thus, in the scientific method, the approach begins with a theory, collects data that either supports or rejects the theory, and then makes necessary revisions before additional tests are made.

The **constructivist** or **interpretivists** believe reality to be socially constructed and can be drawn from subjective points of view. Inductive logic and qualitative methods are employed to find out a particular phenomenon within its social context (Bliss & Rocco, 2013). Creswell (2003) explains that social constructivists assume that individuals seek their own subjective meanings of their experiences. These meanings are varied and multiple, leading the researcher understanding of the world in which they live and work. They rely as much as possible on the participants' views. The research questions are broad and general and participants construct the meaning of a situation. The more open-ended the questioning, the better, as the researcher listens carefully to participants. The process of qualitative research is inductive from generating meaning from the data collected in the field.

The **advocacy** perspective is concerned with social justice. The follower of this claim focuses on people empowerment by social exploitation. They are looking for programs that can change existing practices to foster better lives (Jamil, Askvik, & Hossain, 2013). The participants are active collaborators in advocacy-participatory view (Creswell, 2003).

In **pragmatism**, there are singular and multiple realities in empirical inquiry which leads toward practical problem solving in the 'real world'. The researchers are free mentally and practically from any constraints imposed by post-positivism or constructivism (Feilzer, 2010). The paradigm of this study is pragmatism.

## **Pragmatism**

Creswell (2003) explains that in pragmatism, the problem is more important than the method and all approaches can be used to understand the problem as a philosophical underpinning for mixed methods studies. It can use liberally from both quantitative and qualitative assumptions. The researcher is free to choose the methods, techniques and procedures. Pragmatists do not see the world as an unity. Mixed methods researchers look to many approaches to collect and analyse data. Thus, in mixed methods research, both qualitative and quantitative data will be used to provide the best understanding of a research problem. Pragmatist researcher reject a forced choice between traditional post-positivist' and constructivist' mode of inquiry (Polit & Beck, 2013). Pragmatism, as a philosophy has an emphasis on a theoretical matters on practice (Mounce, 2000). The philosophy of pragmatism described by Charles Peirce (1977) and further developed by William James (1909) and John Dewey (1938). The foundation of pragmatism is:

*The meaning and truth of any thoughts or idea are determined somehow by criteria of practical usefulness, in other words, the value of an idea or proposition is to be found in the practical consequences of accepting it' (Hannes & Lockwood, 2011, p.1636).*

Pragmatists believe that the measurable world has different elements or layers; some objective, some subjective and some a mixture of the two. They suggest that the research should not aim to represent the reality or measure the things accurately, but to be useful, to aim at 'utility for us' (Feilzer, 2010).

Nursing is primarily a pragmatic profession and without further empirical study we cannot provide sufficient evidence in nursing practice (Garrett, 2007). The pragmatists believe in using different paradigms in mixed research, but the researcher should pay attention to each paradigm and to be explicit about when each is used (Kettles, Creswell, & Zhang, 2011). The practical consequences are considered as the vital components of meaning and truth in pragmatism. Truth and meaning are provisional, tentative and subject to change (Dures, Rumsey, Morris, & Gleeson, 2011). Creswell (2003) states that pragmatism provides a basis for the following knowledge claims:

Pragmatism is not limited. This applied to mixed methods research in that the researcher is free to draw from both quantitative and qualitative assumptions.

The researcher is free to choose the methods, techniques and procedures of research to achieve the goals.

In pragmatism; mixed methods researcher looks to many approaches to collect and analyse data (e.g., quantitative or qualitative).

Using both quantitative and qualitative methods lead to the best understanding of a research problem.

For mixed methods researchers, pragmatism opens the door to multiple choices.

When the epistemological concerns should be translated to research methodology; the pragmatic paradigm poses some methodological questions. For example, how can measure all layers of phenomena? Using the mixed methods research offers both quantitative and qualitative methods to measure all aspects of the phenomenon (Feilzer, 2010). All paradigms debate between quantitative and qualitative approaches in their methodological assumptions. The mixed methods research offers a third approach based on pragmatism, which two

methodological approaches can be used in conjunction with another (Teddlie & Tashakkori, 2011).

### **The mixed methods research**

Because of a growth in pragmatic attitudes toward exploring the research questions, the number of researchers adopting a mixed methods approach has increased (Gelling, 2014). It is important to choose a research design that reflects the research questions and not vice versa (Larkin, Begley, & Devane, 2014). It was not very long ago that researchers started combining the qualitative and quantitative research designs. Many researchers called themselves just qualitative or quantitative researchers and, regardless of the research questions; they were adopting their own favourite approach (Gelling, 2014). Holistic care is central to nursing and midwifery philosophies and most of the nursing and midwifery researches aim to bring changes in practice by improving the knowledge. Using statistical measures alone cannot recognize all human experiences like their psychological and emotional aspects. Conversely qualitative studies are often small, use convenience sampling and suffer from the lack of generalizability which lead to be known as less powerful and less influential than quantitative researches. Both quantitative and qualitative approaches are valuable to make the body of nursing and midwifery knowledge (Larkin et al., 2014). The paradigm wars between qualitative and quantitative researches have resulted in mixed methods studies which are a widely used mode of inquiry (Terrell, 2012).

The mixed methods concept was introduced by Jick (1979) as means for exploring convergence across qualitative and quantitative methods within social science research (Creswell, Plano Clark, Gutmann, & Hanson, 2003). There are several definitions for mixed methods that might include methods, research process, philosophy and research design. An early definition of mixed methods came from the field of evaluation authors like Greene, Caracelli and Graham (1989) who emphasized the mixing of methods and paradigms. Then years later; the mixed methods were described as mixing in all phases of the research process and started to be seen as a methodology. Tashakkori and Teddlie (1998) defined mixed methods as combination of quantitative and qualitative approaches in the methodology of study (Creswell, 2011). A few years later; Plano Clark and Creswell (2011) defined the mixed methods by incorporating the diverse perspectives of all previous definition:

*Mixed methods research is the type of research in which a researcher or a team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the purpose of breadth and depth of understanding and corroboration (p.271).*

In this definition mixed methods research is viewed as a methodology rather than methods (Creswell, 2011). Two major paradigms are included in mixed-methods research. The quantitative research ( i.e., a positivist paradigm) which tries to eliminate biases, remain emotionally detached and uninvolved with the object of study and test or empirically justify their stated hypothesis. The qualitative part supports the constructivist paradigm and the research is value-bound which it is impossible to differentiate fully causes and efforts, the logic goes from specific to general and the knower and known cannot be separated because the subjective knower is the only source of reality (Terrell, 2012).When the mixed methods research is done properly, the researcher can have added advantages, but it is important that this approach is used when it is the best one to answer the research questions (Murphy et al., 2014).

Teddlie and Tashakkori (2009) described three advantages of mixed methods research:

- 1-Using both qualitative and quantitative approaches to answer confirmatory and exploratory questions
- 2-Providing stronger inferences
- 3-Offering a greater assortment of divergent views

The major challenge of mixed methods research is the lack of uniformity and absence of clarity as to when and at what level they are mixed (Sandelowski, 2003). Creswell and Plano Clark (2011) mention that using mixed methods will not be easy. It requires skills in several areas: quantitative research, qualitative research and mixed methods research. It is time consuming to gather data from both sources and it needs resources to fund these data collection (and data analysis) efforts. Perhaps most importantly the researcher needs to convince others of the value of mixed methods. Mixed methods design may be fixed and/or emergent. It means that it might be predetermined at the start of the research process or using of mixed methods arises due to issues that develop during the process of conducting the research. However the emergent mixed methods approaches have been recognized more important and more valuable.

There are specific approaches using qualitative and quantitative research procedures and data collection which can be implemented at the design, methods and analysis. At the design level; there are three basic designs :( 1) exploratory sequential, (2) explanatory sequential and (3) convergent designs. In sequential designs; one phase of study build on the other; whereas in convergent design both phases are merged to compare the quantitative and qualitative results. In an exploratory sequential design, the qualitative data is collected and analysed first; but in an explanatory sequential design the researcher first collects and analyses quantitative data and based on findings the qualitative part is done. In convergent design (concurrent design) both qualitative and quantitative data are collected at the same time (Fetters, Curry, & Creswell, 2013).

At methods level; there are two different designs: parallel design (triangulation design) and embedded design. In concurrent triangulation strategy; the qualitative and quantitative data are collected simultaneously with equal priority. The different but complementary data are collected in this method. In an embedded design; one type of data is supporting the other data type. Either qualitative or quantitative data can be dominant. One type of data is collected by two methods to support each other (Creswell & Plano Clark, 2011).

This study mainly aims to explore the mental adjustment to colon cancer over 6 months after diagnosis. The primary design was quantitative method. A pilot study was conducted to assess the feasibility of finding potential participants. The results showed that the number of newly diagnosed colon cancer patients coming to oncology clinics was not enough to cover a quantitative design within a PhD thesis time limitation; therefore, a convergent parallel mixed methods design was selected due to issue of sampling. Bryman (2006) refers to sampling problems as one of reason for mixing methods. The context reason refers to cases in which a qualitative research provides contextual understanding and the quantitative research improves either generalizable, externally valid findings or broad relationships among variables uncovered through a survey. The convergent mixed methods design with a concurrent strategy was used in this research.

### **Convergent parallel mixed methods design**

In addition to using fixed and emergent designs, researchers need to choose an approach for designing their mixed methods studies. There is a range of classifications of mixed methods designs. Creswell and Plano Clark (2011) list 15 classifications based on many disciplines,

including evaluation, health sciences, and education since the late 1980s. They advanced a parsimonious and functional classification including six designs: the convergent parallel design, the explanatory sequential design, the exploratory sequential design, the embedded design, the transformative design and the multiple designs. The four major types of mixed methods designs are the Triangulation Design, the Embedded Design, the Explanatory Design, and the Exploratory Design.

The most common mixed methods approach is the triangulation design. In this design different but complementary data on the same topic are obtained to understand the research problem. The purpose is to bring together the different strengths and non-overlapping weaknesses of quantitative methods with those of qualitative methods. The researchers use this design to compare quantitative statistical results with qualitative findings or to validate or expand quantitative results with qualitative data. The triangulation design is a one-phase approach in which researchers implement the quantitative and qualitative methods during the same timeframe and with equal weight. The single-phase timing of this design is the reason it has also been referred to as the “concurrent parallel design” (Creswell, 2003).

In a convergent design (concurrent design), both qualitative and quantitative data are collected and analysed at the same timeframe. Sometimes an interactive approach may be employed where data collection and analysis make changes in data collection procedure. In the other words, qualitative and quantitative data collection occurs in parallel and analysis begins after completion of data collection. The qualitative and quantitative data are analysed separately and then merged all together (Creswell & Plano Clark, 2011).

A convergent parallel mixed methods design was chosen in this study. The purpose of choosing this design was to answer the same research questions by using both methods. Both qualitative and quantitative data were collected and analysed concurrently and findings were merged together.

## **Theoretical Framework**

Theory is defined as an abstract generalization to explain how phenomena are interrelated. The theories help to make research findings meaningful and interpretable. Theories may show “what” the natural phenomena are and “why” they occur. Theories provide both direction and impetus to stimulate research. They vary in their level of generality. Grand theories describe large segment of human experiences. There are grand theories which explain the whole of nursing. Middle-range theories explain such phenomena as stress, comfort and health

promotion. In empirical testing; the middle-range theories are more specific and more amenable (Polit & Beck, 2013).

In nursing, science is the result of research and theory interaction. Research should develop within a theoretical structure which facilitates analysis and interpretation of finding. Nursing practice is based on the theories that are generated and validated through research (LoBiondo-Wood & Haber, 2013). Some theories are not unique to nursing. Bandura's social-cognitive theory; which is sometimes called self-efficacy theory offers an explanation of human behaviour using the concepts of self-efficacy, outcome expectations and self-regulation. This theory is one of the non-nursing theories that have frequently been used in nursing (Polit & Beck, 2013).

SCT provides a theoretical framework to evaluate psychosocial interventions for cancer patients. Treatments and interventions based on SCT can help to increase and even maintain the positive health behaviours. The mechanisms of positive change within psychosocial interventions can be evaluated through SCT's components of self-efficacy, outcome expectation and self-regulation (Graves, 2003).

Mental adjustment to cancer is one of the important factors correlating with quality of life and psychological distress. Some studies have shown that it may even affect the physical outcomes (Akechi, Okamura, et al., 1998). Accurate assessment of mental adjustment to cancer is important, because psychological morbidity associated with cancer has been shown in many studies (Greer et al., 1989) and the type of coping strategies is an important determinant of such morbidity (Watson et al., 1984). Psychological response to cancer may affect the duration of survival (Watson et al., 1999).

The SCT can be an effective framework in increasing and even maintaining positive health behavior. The three components of the SCT self-efficacy, outcome expectations and self-regulation are the predictors of positive changes in psycho-oncology. This positive change for cancer patients is improved quality of life (Graves, 2003).

Mental adjustment to cancer was assessed through this theoretical lens in this study.

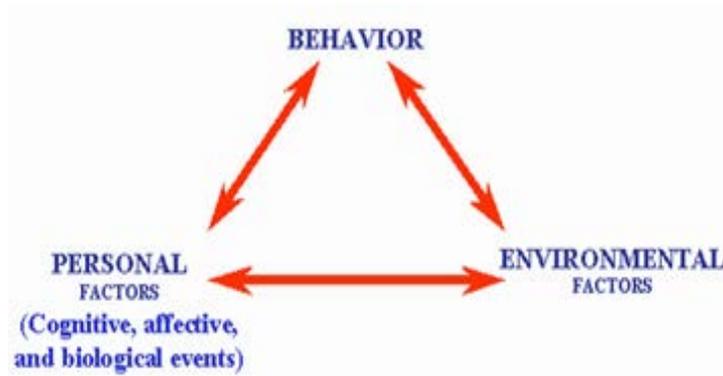
### **Bandura's socio-cognitive theory**

Social cognitive theory explains the process of learning based on observation. This model can be used for dealing with different situations (Bandura, 1998). Observational learning refers to

learning process through watching the actions of another person and the reinforcement that the person receives (Bandura, 1997). Many theories have tried to explain the developmental changes over the course of life (Bandura, 2011). Neal E. Miller and John Dollard proposed the theory of social cognitive learning in 1941. This theory was developed by Canadian psychologist Albert Bandura. He introduced a learning theory with more emphasis on the cognitive processes. The SCT suggests that learning and behavior (cognition) have a reciprocal relationship with environment (Bandura, 2001). It has been used in many areas and learning achievements (Lent, Brown, & Hackett, 2002). The SCT describes how people learn and maintain certain behavioral patterns (Bandura, 1997).

Bandura developed a model of cognitive, vicarious, self-regulatory and self-reflective process in human adaptation and change. In this theory the person is a self-organizing, proactive, self-reflecting and self-regulating rather than as simple reactive person who responds to environmental factors. Though, social-cognitive theory explains that human's behavior is the result of reciprocal and dynamic interplay of (a) personal factors (e.g. cognition, affect), (b) behavior and (c) environmental influences (Bandura, 2001) (Figure 3.1). Environment refers to the factors which can affect the behavior. There are social and physical environment. Social environment can be described as family members, friends and colleagues. Physical environment can be the size of a room, the temperature or the availability of certain foods. These three factors environment, people and behavior are constantly influencing each other. Behavior is not just the result of the environment and the person; just as the environment is not the only result of the person and behavior. The behavioral change can be evaluated based on the factors environment, people and behavior. There are social or physical environments and the environment and situation can help to understand the behavior. These three factors are constantly influencing each other (Glanz et al., 2002).

People have an agency or ability to influence their own behaviour and environment in a purposeful, goal-directed fashion in this theory. SCT believes that people can exert substantial influence over their own outcomes and the environment by forethought, self-ref-reflection and self-regulatory process (Denler et al., 2014). This theory emphasizes that social and cognitive changes depend on the individual and their social network. Patients and their social attachments respond and cope with the crisis in their lives and draw conclusions from that crisis. This conclusion may be the source of psychological distress and subsequent disorder, but can be the source of "post-traumatic growth" (Brennan, 2001). The SCT explains how people learn and maintain behaviours (Bandura, 1997).

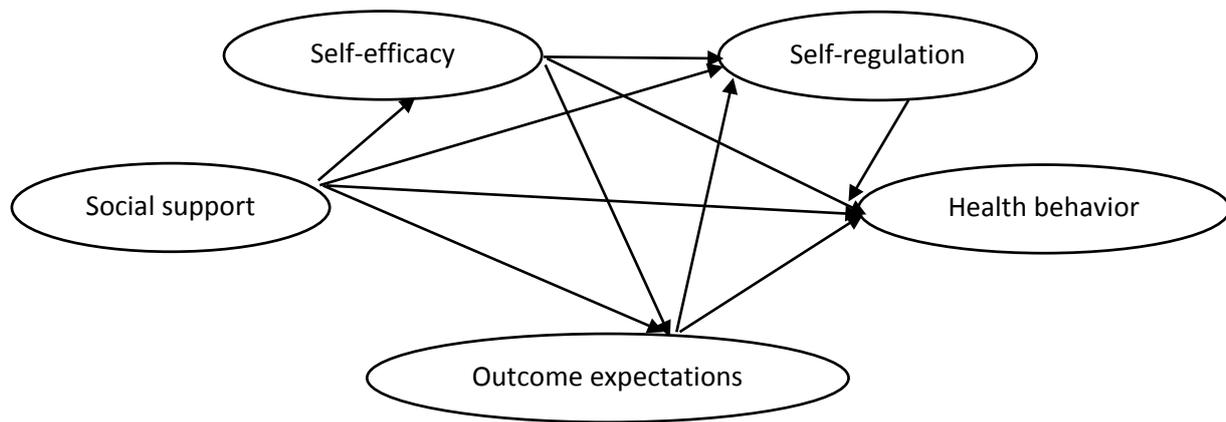


*Figure 3.1 Reciprocal determinants of social cognitive theory*

Social cognitive theory can be used for health promotion and disease prevention. It helps to recognize the determinants and the mechanism of the health practices and identifies the optimal ways of translating of this knowledge to practice. The perceived self-efficacy seeks how one can exercise control over one's health habit and the outcome expectation reveals the expected costs and benefits for different health habits (Bandura, 1998). Brennan (2001) describes the SCT model as a broad conceptualization model of adjustment. This model attempts to account both positive personal growth as well as psychological disorders. This model builds on concept from the coping, social cognitive and traumatic stress literatures using the complementary assets of social cognitive and copying theory. It is a model of normal adaptation in which the individuals and their social world attempts to make sense of changes imposed by the cancer and its treatments.

One of the strengths of this theory is that the conditioning is not mentioned as the only method of learning. This theory emphasises on the importance of the relationship between behaviour and environment and social environment is considered as an effective factor. It is an open theory which can be used in many researches. The lack of uniformity is one of the main criticisms of SCT. It is a broad theory and all of its component parts are not fully understood. The findings associated with this theory are preliminary and it does not have a full explanation or description of social cognition. The SCT ignores maturation and it does not differentiate between children and adults observational learning("Evaluating the Social Cognitive Perspective on Personality," 2014).

Bandura’s social-cognitive theory; offers an explanation of human behaviour using the concepts of self-efficacy, outcome expectations and self-regulation. The social environments (family members, friends and colleagues) can help to understand the behavior.



*Figure 3.2: The theoretical framework of SCT (Anderson-Bill, Winett, & Wojcik, 2011)*

## Self-efficacy

It is the “belief in one's capabilities to organize and execute the course of action required to produce given attainments”. This ability predicts more adaptive psychological and physiological functioning in both healthy and ill population. The self-efficacy has been shown to impact on health predictors and adaptation to illness and treatment (Bandura, 1997). Self-efficacy reflects an individuals’ beliefs about if they can achieve a certain level of successful at a particular task. The greater self-efficacy leads to more confidence in the abilities to be successful (Denler et al., 2014). The more being confident in ability the higher probability of attaining some goals such as maintaining a desired state of quality of life will be achieved. The cancer patients who feel more efficacious about their coping capacity are better adjusted (Merluzzi, Nairn, Hegde, Martinez Sanchez, & Dunn, 2001). Self-efficacy is as a product of past performances, the observation and verbal persuasion of others in the environment and the physiological state (Denler et al., 2014). Self-efficacy is a dynamic factor that changes with

experience and strong self-efficacy beliefs predict adjustment to cancer diagnosis (Graves, 2003).

## **Self-Regulation**

Self-regulation refers to the process of planning, monitoring, and changing one's behaviors and cognitions to correspond with abilities, the environment, and desired outcomes. People are capable of self-regulation by influencing direct control over their own behavior and by selecting or altering environmental conditions that, in turn, influence their behavior. People adopt personal standards for behavior, appraise their behavior against such standards, and create unique incentives that motivate and guide their behavior (Maddux & Meier, 1995). Self-regulation is an important aspect of SCT that explains assumption regarding agency and the influence of personal factors on behavior and the environment. It is also dependent on the processes within SCT including goal setting and self-efficacy (Denler et al., 2014). The active process of self-regulation may contribute to positive adjustment for cancer patients, because avoidant coping styles have been shown to predict poorer outcomes (Stanton & Snider, 1993).

## **Outcome Expectations**

Outcome expectations indicate beliefs about what consequences are most likely to happen if particular behaviors are performed (Denler et al., 2014). It refers to the physical, social, and self-evaluative expectations one holds for the outcome of one's behaviors. An outcome expectation is a perception of current and potential future outcome and is described as the “subjective probability that a particular behavior, if performed by someone at a given level of competence, will be followed by a particular outcome” (Kirsch, 1995). Outcome expectations are important in SCT because they help people to decide about what actions to take and which behaviors to suppress. When the outcome expectations are valued, the frequency of behavior should be increased, whereas behaviors associated with unfavorable or irrelevant outcomes will be suppressed (Denler et al., 2014). While cognitions and expectations are appropriately realistic and stated positively, cancer patients experience less distress. Specifically, interventions to improve QOL aim to teach cancer patients how to recognize and restructure negative expectations about their illness and the future (Greer et al., 1989).

## Methods

The main aim of this study was to explore changes in mental adjustment to the diagnosis of colon cancer over time. Mental adjustment has been identified as a cognitive and behavioural response with 5 dimensions: fighting spirit, helplessness/hopelessness, anxious preoccupation, fatalism and avoidance. This study aims to identify how these dimensions change over time and how they are correlated with socio-cognitive theory constructs. So, we can conclude which dimensions are related to learning to live with this new situation. A convergent parallel mixed methods design was chosen. This design allowed for the same research questions to be explored through both methods. The longitudinal design was used to explore the changes over a 6 month period.

## Research Questions

For this study the following two research questions and sub-questions were developed:

**1-How does mental adjustment to colon cancer change over 6 months following diagnosis?**

**2-How is mental adjustment to colon cancer correlated to the socio-cognitive theory constructs?**

-How is self-efficacy correlated to mental adjustment to colon cancer?

-How is self-regulation correlated to mental adjustment to colon cancer?

-How is outcome expectancy correlated to mental adjustment to colon cancer?

-How is social support correlated to mental adjustment to colon cancer?

## Aim

This study aimed to investigate the mental adjustment to colon cancer within the framework of Bandura's social-cognitive theory. This theoretical lens provided a framework for this study, therefore self-efficacy, self-regulation, outcome-expectancy and perceived social support were assessed and the correlations between these concepts with the mental adjustment to cancer were explored. This study had two aims:

- (i) To explore the mental adjustment changes to colon cancer over a 6 month period following diagnosis
- (ii) To determine the relationship between the mental adjustment to colon cancer and SCT's constructs

## **Setting**

The study was conducted at the oncology outpatient clinic of a large tertiary teaching and research hospital. The oncology department at this hospital has a dedicated oncology day ward which delivers chemotherapy treatment. This medical oncology service sees approximately 7000 patients per year and an average of 25-30 chemotherapy treatments are delivered Monday to Friday. The majority of newly diagnosed patients with early colon cancer are referred to an Oncologist at the oncology outpatient clinic after surgery. In the out-patient clinic the patient meets the Oncologist and the nurse to discuss the benefit of any chemotherapy treatment.

The researcher met participants at the outpatient oncology clinic. The interviews were done at patient's home, outpatient oncology clinic or centre of postgraduate nursing studies based on each patient's preference.

## **The pilot study**

A pilot study was conducted in February – May 2014. The aims of the pilot study were:

- To assess the feasibility of finding potential participants by the Oncologist
- To assess the suitability of the questionnaire pack from the participant's perspective
- To assess and promote the principles of minimising harm, maintaining confidentiality and minimising distress with this vulnerable population

All patients with newly diagnosed colon cancer attending the Oncology outpatient clinics were invited to participate in the study. The researcher explained the aims of the study briefly and if patients were interested gave them an information sheet, the consent form and the questionnaires with a prepaid envelope to take home. Thirteen patients showed interest in the study and ten questionnaires were sent back to the researcher. In addition to the questionnaires patients were asked to report how they found completing the questionnaires. The questions were:

- Did you find completing the questionnaires took too long?
- Did you find any of the questionnaires difficult to complete?
- Would you be interested in taking part in a short interview?

The patients were asked to put any comments about how they felt during completing the questionnaires at the bottom of this sheet.

The pilot study showed that participants did not find completing the questionnaires challenging or that this took too much time. Participants also showed an interest in participating in a short interview.

There were 3-4 newly diagnosed colon cancer patients attending the clinics every week, but many were not able to join the study. The pilot study showed that there were not sufficient participants within the time frame to cover an extensive quantitative data collection. An embedded qualitative strand within a quantitative part was chosen for the main study.

## **Ethical Approval**

Ethical application for this study was sought from the University of Otago human ethics committee (health), which was declined on 30 October 2013. The committee noted a number of significant questions posed by the peer reviewer of the study and did not feel the issues or the concerns of the committee had been answered satisfactorily and that the cancer patients might feel distressed during the study.

The pilot study was therefore designed and an ethical application for it accompanying a cover letter explaining those concerns was submitted. The ethical approval for the pilot study was granted on 24 January 2014. The pilot study found that participants did not find completing the questionnaires challenging or that this took too much time.

The main protocol was sent for another peer review, with answers to all questions raised by peer reviewer, and another ethical application was made to start the main study. The Committee was of the view that the application form needed to be revised to include the selection criteria correctly presented with amended exclusion criteria to specify not rectal, no prior adjuvant therapy. The Committee also asked that the title of the study was modified to refer to “colon cancer” and not “colorectal cancer”. Ethical approval was granted on 19 May 2014.

The locality authorisation for Canterbury District Health Board approved the conduct of the study at Christchurch hospital.

## **Maori Consultation Process**

This study aimed to find the pattern of mental adjustment to cancer in both Maori and non-Maori newly diagnosed colon cancer patients. Comprehensive and detailed data on Māori and non-Māori cancer patterns and disparities are essential for current and future cancer control policy and programs.

A meeting with Wendy Dallas-Katoa, acting research manager-Maori, University of Otago, Christchurch was arranged on the 16<sup>th</sup> May 2013 to discuss any issues regarding to Maori participants in this study.

The need to ensure that ethnicity data is collected from each participant was highlighted. Māori communities have the right to a high-quality, comprehensive evidence base to inform cancer control strategies, service development and community interventions, as well as to enable monitoring for equity of access and outcomes.

## **Design**

A longitudinal design was used to track the changes over a 6 months period. Data were collected at 2 time points:

- after surgery at first appointment at outpatient Oncology clinic
- 4-6 months after surgery

The longitudinal surveys are undertaken over long periods of time and allow researchers to detail changes or trends over time (le May & Holmes, 2012). In cohort studies ('cohort' means a group of people), a common characteristic among a sample of individuals is examined. The crucial feature about longitudinal cohort studies is that researchers look forward and track a group of people over a period of time (Maltby, Williams, McGarry, & Day, 2014).

## **Sample**

All patients with a new diagnosis of colon cancer attending the oncology outpatient clinics were eligible to participate. The purposive sampling was used. The pilot study showed that approximately between 2-4 newly diagnosed colon cancer patients attended the clinics every week. All newly diagnosed colon cancer patients with inclusion criteria were invited to participate in this study.

### **The Inclusion criteria were:**

- Ambulatory non-metastatic patients with colon cancer
- Patients aware of the diagnosis of cancer
- Post-surgery
- 18 years of age or older
- Able to consent to the study and independently complete questionnaires

### **The Exclusion criteria were:**

- Severe physical or mental impairments
- Previous history of malignant disease
- no prior adjuvant therapy

Whilst some patients do have a long journey before undergoing surgery, the majority do not. One of the study exclusion criteria was pre-operative chemotherapy or radiation, so those patients who had undergone treatment before surgery were excluded. Most patients with colon cancer had up-front surgery, unless they had metastatic disease, when chemotherapy may be given and surgery not undertaken. The participants in this study had a diagnosis of colon cancer, had completed their surgical care and been referred to oncology for consideration of adjuvant chemotherapy. In this respect they were a uniform group, possible complexity was accommodated and the study group designed to be relatively homogenous.

## **Data Collection**

Data collection for time point one commenced in June 2014. All patients newly diagnosed with colon cancer and referred to an Oncologist after surgery were potential participants. The list of all appointments was reviewed by a research nurse at the clinic one week in advance and the times of appointments were e-mailed to the researcher. Either the oncologist or the nurse asked the patient whether they agreed to meet with the researcher and the researcher attended the clinic to meet the patients after their meeting with the oncologist and nurse. If the patient agreed to meet with the researcher, the researcher briefly explained the study and gave them the information sheet and the consent forms with a pre-paid envelope to take home to read. If the patients were interested in participating in the study, they sent a consent to be contacted form back. The researcher contacted the patient to arrange an interview and completion of questionnaires. The oncologist and the nurse made the first contact regarding the research and assessed if they thought a patient might feel too distressed to meet the researcher, if this was the case they did not discuss the study with patient.

All interviews were arranged by phone and took place at patients' homes, clinics or researcher's workplace. After 4-6 months all participants were asked to complete the same questionnaires again and another interview was arranged.

## **Qualitative data collection**

Using a semi-structured interview, the concepts of the study including mental adjustment to cancer, self-efficacy, self-regulation, outcome expectations, social support and general health status were explored through a set of open-ended questions. Each interview took approximately 30-45 minutes.

Some participants agreed to be interviewed again 4-6 months later and very few changes to the questions were made. All interviews were recorded and transcribed verbatim.

## **Quantitative data collection**

All participants received a pack of questionnaires to complete at the first and second time point of study.

## **Research instruments**

The researcher and supervisors discussed and reviewed all possible research instrument options. The psychometric properties and previous use of measures were checked to assess these concepts.

### **Demographic and disease information**

In order to collect demographic and disease information twelve questions were developed. General information related to gender, age, date of surgery, received treatments, marital status, level of education, employment status, annual income, living area, ethnic group, religious preference and people living with patients were sought.

### **Mini-Mac Scale**

The Mental Adjustment to Cancer Scale (Watson et al., 1988) was designed to provide a method of assessing specific responses to cancer. The aim was to develop a self-rating questionnaire acceptable to cancer patients, which could be administered easily during busy oncology clinics. The MAC Scale does not attempt to measure every possible coping response; a detailed exposition of a more complex rating method has been described elsewhere (Morris et al., 1985). This scale was originally developed using a 58-item questionnaire in a heterogeneous sample of 235 cancer patients. The exploratory factor analysis led to develop a 40-item questionnaire including five dimensions: Fighting Spirit (FS), Hopelessness/Helplessness (HH), Anxious Preoccupation (AP), Fatalism (FA) and Avoidance (AV) (Watson & Homewood, 2008).

The Mini-Mental Adjustment to Cancer Scale (Mini-MAC) was extracted from the MAC which it has still five sub-scales and is now often used in preference to MAC in clinical settings due to brevity. The Mini-MAC is a 29-item self-rating questionnaire developed in response to the limitation of the original MAC Scale (Watson et al., 1994). This questionnaire included the same five dimensions but fewer items for ‘fighting spirit’ (4 questions), ‘hopelessness/helplessness’ (8 questions), ‘anxious preoccupation’ (8 questions), ‘fatalism’ (5 questions) and ‘cognitive avoidance’ (4 questions). It takes less time to complete and is more suitable for distressed cancer patients (Kang et al., 2007). The Mini-MAC has been translated into several other languages. Aside from the original psychometric data in the 1994 paper, we are aware of no subsequent publication that provides validity and reliability data for the English

version of the Mini-MAC (Hulbert-Williams, Hulbert-Williams, Morrison, Neal, & Wilkinson, 2012). The internal reliability coefficients of the Mini-MAC subscales were reported to be satisfactory ( $\alpha$  coefficients 0.62–0.88) (Watson et al., 1994).

### **Self-Efficacy Scale**

The self-efficacy scale assesses a general sense of perceived self-efficacy with the aim to predict coping with daily hassles as well as adaptation after experiencing all kinds of stressful life events. It was developed first in German version by Matthias Jerusalem and Ralf Schwarzer in 1979. It has been revised and translated to 26 other languages by various co-authors. This scale can be used for the general adult population. The construct of this scale reflects an optimistic self-belief and how the one can perform difficult tasks or cope with adversity (Jerusalem, Schwarzer, & Schwarzer, 1992). Ten items are designed in this scale and each item refers to successful coping and implies an internal-stable attribution of success. The Cronbach's alphas have been reported from 0.76 to 0.90. The criterion-related validity has been documented in numerous correlation studies where positive coefficients were found with favourable emotions, dispositional optimism and work-satisfaction. Negative coefficients were found with depression, anxiety, stress, burnout and health complaints. This scale can be used to predict adaptation after life changes (Schwarzer & Jerusalem, 1995).

### **Cognitive Emotion Regulation Questionnaire (CERQ)**

The perception of personal agency which is the core of sense of self determines the human regulatory skills (Zimmerman, 2000). The concept of emotion regulation is defined as 'all the extrinsic and intrinsic processes responsible for monitoring, evaluating and modifying emotional reactions' (Gross, 1999).

The CERQ was developed to assess what someone thinks after the experience of threatening or stressful events (N. Garnefski & Kraaij, 2006a). This questionnaire assesses what someone thinks after the experience of threatening or stressful events (N. Garnefski & Kraaij, 2007). The CERQ is a multidimensional questionnaire to assess the cognitive coping strategies after negative events or situations. It is a 36-item questionnaire, consisting of nine conceptually distinct subscales: Self-blame, Other-blame, Rumination or focus on thought, Catastrophizing, Putting into Perspective, Positive Refocusing, Positive Reappraisal, Acceptance and Refocus on Planning. A short 18-item version of the Cognitive Emotion Regulation Questionnaire (CERQ-short) was developed by reducing the number of items per scale from four to two (N.

Garnefski & Kraaij, 2006a). The internal consistency of the nine CERQ scales was computed and reported as good to very good (in most cases were over 0.70). A test-retest correlation range between 0.48 and 0.65 which shows that it is reasonably stable styles, although certainly not comparable to personality traits (N. Garnefski, Kraaij, & Spinhoven, 2002).

### **Revised Life Orientation Test (LOT-R)**

Outcome expectation is the other factor that defines the interactions of the individual with environment in Bandura's theory. It is a perception of current and potential future outcome (Kirsch, 1995). The differences in outcomes can be described as optimists and pessimists. And most of the researches on optimism and pessimism have used the Life Orientation Test (LOT) (Scheier & Carver, 1985).

Scheier and Carver (1985) developed The Life Orientation Test (LOT) to measure optimism. This test has been used in several studies in health and personality psychology. The LOT is a self-report measure including eight items and four filler items. Responses are made on 5-point Likert scales ranging from 0 (strongly disagree) to 4 (strongly agree). Scheier and Carver (1985) reported a Cronbach's alpha of 0.76 and a test-retest correlation of 0.79 over a 4 week period (Andersson, 1996). This scale possesses adequate predictive and discriminant validity (Scheier, Carver, & Bridges, 1994).

### **Multidimensional Scale of Perceived Social Support (MSPSS)**

Since the mid-1970s the role of social support has been concerned as a coping resource (Zimet, Dahlem, Zimet, & Farley, 1988). Zimet et al. (1988) developed the 12-item Multidimensional Scale of Perceived Social Support (MSPSS) which is easy-to-use and time-effective and seeks the perceived social support from three sources: family, friends and a significant other (Dahlem, Zimet, & Walker, 1991).

Zimet et al. (1988) demonstrated a strong test-retest reliability, internal reliability and factorial validity for MSPSS.

### **SF-12V2 Health Survey**

The SF-12V2 Health Survey is a 12-question survey developed to measure the overall health. The completion of this survey just takes 3 minutes. This is a practical, reliable and valid measure of physical and mental health. This scale is a widely used tool to assess population

health, comparing and analysing disease burden and predicting medical expenses. The SF-12 is a multipurpose short questionnaire with 12 questions selected from the SF-36 Health Survey which assesses health-related quality of life. It consists 12 items addressing 8 domains including: Physical functioning (PF), Role – physical (RP), Bodily pain (BP), General health perceptions (GH), Vitality (V), Social functioning (SF), Role – emotional (RE) and Mental health (MH) as well as physical component summary (PCS) and mental component summary (MCS). Many studies have shown that the SF-12 is a reliable and valid instrument which can be used in a variety of population groups. (QualityMetric, 2002).

## **Data analysis**

### **Qualitative data analysis**

All interviews were transcribed by a confidential transcription secretary who was introduced by centre of postgraduate nursing studies of University of Otago. The interviews were transferred from recorder to the researcher's computer and e-mailed to transcription secretary who transcribed them and e-mailed them back. The transcriptions were checked against the recorded interviews by researcher and they imported to the NVIVO 10 for windows as data files. Data analysis of transcripts was conducted using the process of a directed (deductive) content analysis.

The content analysis has been defined as a research methodology that uses procedures to make valid inferences from text (De Wever, Schellens, Valcke, & Van Keer, 2006). Researchers calls content analysis as a flexible method for qualitative data analysis (Hsieh & Shannon, 2005). It has been used in many studies but little has been published how to apply the method. Through content analysis, the words are distilled into fewer content-related categories and phrases in each category share the same meaning. A condensed and broad description of the phenomenon is provided by this method and the outcome of the analysis is concepts or categories. The researcher decides to choose either the terms 'concept' or 'category' (Elo & Kyngäs, 2008).

Initially, the content analysis was used as either qualitative or quantitative method, but later was considered as a quantitative analysis of qualitative data. Recently, the content analysis is a qualitative analysis method for health researcher with an increasing application and popularity. The qualitative content analysis is used to analyse text data and focuses on the characteristics of language and communication with consideration of content or contextual meaning of the text (Hsieh & Shannon, 2005).

The first decision in content analysis method is selecting the unit of analysis. The most suitable unit of analysis is whole interviews which are large enough to be considered a whole and small enough to be possible to understand as a context for the meaning units. A meaning unit is words, sentences or paragraphs including aspects related to each other by their content or context. The next step in the analysis process is condensation, as it refers to the process of shortening while still preserving the core. The condensed texts are abstracted. The abstraction is describing and interpreting the condensed texts in a higher logical level. The codes, categories and themes are created at this level. Creating categories is the main part of a qualitative content analysis. A category is a group of contents that transfer a commonality. A category usually includes a number of sub-categories. The sub-categories can be abstracted into a category or a category can be divided into sub-categories (Graneheim & Lundman, 2004).

Conventional content analysis is used to describe a phenomenon when existing theory or research literature on it is limited. In this method, the researchers avoid using pre-defined categories. In directed content analysis, an existing theory or prior research is used to define each category. Data are coded using predetermined codes and those which cannot be coded are presented as a new category or sub-category. Depending on the type and breadth of categories, sub-categories might need to be identified. The prior research used will guide the discussion of findings (Hsieh & Shannon, 2005).

Using a directed content analysis method in this study, the operational definitions of the five dimensions of mental adjustment to cancer were developed based on Greer and Watson (1987) explanations including :

**-Fighting spirit:** this is a confrontative coping response and patient is optimistic toward the future and believes in possible some control over the illness. The diagnosis of cancer is fully accepted and the term “cancer” is used. Patient is determined to fight the illness and tries to explore as much information as possible. The illness is seen as a challenge and an optimistic view is taken. Some examples are as following: ‘I won’t let cancer beat me, I’m trying everything to get better, I go to these classes to learn to relax and to think positively’, ‘At first I was devastated, but now I realized I’ve got too much to live for...’ I believe with the help of the doctors, I can get well’.

**-Helplessness/hopelessness:** patient sees the prognosis inevitable and negative. He/she thinks it is impossible to control over the illness. There are no active strategies for fighting the illness.

Patient think about the diagnosis all the time and cannot think of anything else. Fears and possibly death have disrupted daily life and a wholly pessimistic attitude is adopted. Examples include: 'There's nothing they can do, I'm finished', 'I feel hopeless a lot of the time, I keep worrying about it and cry a lot... can't get it out of my mind, I don't know what to do'.

**-Anxious preoccupation:** there is an uncertainty over the control of disease. The disease is seen as a major threat. Searching compulsively for reassurance is seen as behavioral coping responses. Patient reacts to the diagnosis of cancer with anxiety and depression. He/she seeks information but tends to interpret them pessimistically. Any aches or pain is interpreted as spread or recurrence of cancer. He/she tries to seek various 'cures' including alternative treatments. Examples are: 'I keep worrying about it coming back', 'I get this pain in the shoulder here, what do you think it is doctor?', 'I know it's cancer, I can't stop thinking about it, I've gone to this man who does acupuncture and someone told me about meditation, do you think it helps?

**-Fatalism:** the diagnosis is seen as a minor threat which it is impossible to control it. There are no confrontative strategies and the disease is accepted passively. Patient does not seek further information and adopts a fatalistic attitude. Examples are: 'I know what it is, I know it is cancer, but I've just got to carry on as normal, there's nothing I can do'. 'It's cancer. I don't dwell on it try not to think about it, I leave it all to the doctor'.

**-Avoidance (denial):** the patient believes in a minimal threat about the diagnosis and there is a positive view of the prognosis and irrelevant control. Patient refuse to accept diagnosis of cancer and avoid using word 'cancer'. Examples are: 'The doctor's just took my breast off as a precaution'. 'There could have been a few cancer cells but it wasn't serious, there's nothing to worry about'.

At next step, all transcripts were reviewed carefully and all text that appeared to describe a mental adjustment to cancer category were highlighted. The highlighted texts were coded using Greer and Watson (1987) mental adjustment to cancer categories. After coding, the data for each category were examined to determine sub-categories for a category. The findings were reported by rank order of incidence of codes representing the mental adjustment to cancer categories.

The trustworthiness of the qualitative stage of this research was guided by attention to credibility, dependability and transferability. Credibility deals with the focus of the research and refers to confidence in how well data and processes of analysis address the intended focus.

Selecting the most appropriate method for data collection and the amount of data are important in establishing credibility. Another critical issue for achieving credibility is to select the most suitable meaning unit. Credibility of research findings also deals with how well categories and themes cover data. One way to approach this is to show representative quotations from the transcribed text. Another way is to seek agreement among co-researchers, experts and participants. The process of data analysis and how this was managed between the researcher, supervisor and co-supervisors were clarified and described earlier in the study. Dependability was addressed by exploring the same areas for all the participants at both data collection stages. Transferability can be enhanced through providing a clear and distinct description of culture and context, selection and characteristics of participants, data collection and process of analysis. The participants' demographic characteristics and representative quotations from the transcribed texts are presented in the qualitative findings chapter.

### **Quantitative data analysis**

All quantitative data were entered into IBM SPSS statistics 22. A biostatistician advised sampling and consultation continued during the analysis phase. Descriptive statistics were used to present participants' demographic characteristics and scores of all questionnaires at both time points of study. The paired t-tests were run to explore differences over time on the mental adjustment to cancer sub-scales.

The relationship between SCT's constructs with measures on the mental adjustment to cancer sub-scales at two time points were investigated using "Pearson product-moment correlation coefficient". Prior to conducting the analysis, the assumption of normal distribution was estimated and the assumption was considered statistically satisfied. In regards to sample limitation, consultation with the biostatistician recommended that a sample size of 20 would be enough to detect changes over time.

## **Chapter Four**

### **Qualitative results**

#### **Introduction**

This chapter presents findings from the interviews with participants exploring changing mental adjustment strategies over time in relation to constructs of socio-cognitive theory. Participants' demographic data are provided and themes arising from the interviews are described and illustrated. The themes are presented in a chronological order range from participants' responses immediately after receiving diagnosis of colon cancer, while awaiting surgery, immediately after surgery in the hospital setting, before starting adjuvant chemotherapy and 4-6 months after surgery.

#### **Participants' demographics**

Twenty five people newly diagnosed with colon cancer were invited to participate in this study and from those sixteen participants took part in the stage one interviews. Twelve of the sixteen participants who had taken part in stage one agreed to participate in stage two interviews.

All stage one participants were New Zealand Europeans and over 62% were male and more than 56% were over seventy years old. Fifty six percent were married and 44% were living with their husband/wife or partner. Thirty one percent of participants reported completing high school but not to year thirteen and had no religious affiliation. They all owned their houses and 69% were living in an urban area. An annual income of \$10,000-29,000 was reported by 44% of participants.

All stage two participants were New Zealand Europeans; 58% of them were male and over seventy years old. Sixty seven were retired and 50% had an annual income of \$10,000-29,000. Thirty three percent reported not completing year thirteen at high school and 42% had no religious affiliation. Fifty six percent were married and half of the participants were living with their husband/wife or partner. They all owned their homes and 67% were living in an urban area (table 4.1).

**Table 4.1: Socio-demographic characteristics of participants at stage-one and stage-two**

variable		Stage-one		Stage-two	
		Number	Percentage	Number	Percentage
Gender	Male	10	62.5	7	58.33
	Female	6	37.5	5	41.66
Age	40-49	1	6.25	1	8.33
	60-69	6	37.5	4	33.33
	>70	9	56.25	7	58.33
Employment status	Employed	3	18.75	2	16.66
	Self-employed	1	6.25	0	0
	Unable to work	2	12.5	2	16.66
	Retired	10	62.5	8	66.66
Ethnic group	New Zealand European	16	100	12	100
Marital status	Married	9	56.25	7	58.33
	Divorced	3	18.75	3	25
	Widowed	1	6.25	0	0
	Separated	1	6.25	1	8.33
	Never been married	1	6.25	0	0
	Couple living together	1	6.25	1	8.33
Level of education	Unassigned	2	12.5	2	16.66
	High school not to year 13	5	31.25	4	33.33
	High school completed year 13	3	18.75	2	16.66
	Some units at university	1	6.25	1	8.33
	Bachelor's degree	4	25	3	25
	Master's degree	1	6.25	0	0
Total annual income	Unassigned	2	12.5	2	16.66
	\$10,000-29,000	7	43.75	6	50
	\$30,000-49,000	6	37.5	4	33.33
	\$70,000-99,999	1	6.25	0	0
Home area	Urban	11	68.75	9	75
	Rural	5	31.25	3	25
Home status	Owned	16	100	12	100
Religious preference	Unassigned	1	6.25	0	0
	Protestant	4	25	3	25
	Catholic	2	12.5	2	16.66
	Jewish	1	6.25	1	8.33
	Others	2	12.5	1	8.33
	No religious affiliation	5	31.25	5	41.66
	Prefer not to say	1	6.25	0	0
House hold	Husband/wife or partner	7	43.75	6	50

Friends	1	6.25	1	8.33
Family	3	18.75	2	16.66
Living alone	5	31.25	3	25

## Immediately after receiving a diagnosis of colon cancer

Participants tried to remember their feelings when they first heard about their diagnosis of colon cancer.

All highlighted responses were coded using pre-determined categories based on the mental adjustment to cancer scale of Greer and Watson (1987): ‘**Anxious preoccupation**’, ‘**Fighting spirit**’, ‘**Hopelessness/helplessness**’, ‘**Cognitive avoidance**’ and ‘**Fatalism**’. No new main category was needed. After coding, data were examined for each category to determine sub-categories. ‘**Fighting spirit**’ was divided into two categories: ‘**Cognitive fighting spirit**’ and ‘**Active fighting spirit**’. After receiving a diagnosis of colon cancer, ‘**Anxious preoccupation**’, ‘**Cognitive fighting spirit**’ and ‘**Hopelessness/helplessness**’ were reported as the most frequently used adjustment response whereas ‘**Fatalism**’ was the least used (Table 4.2).

**Table 4.2: Mental adjustment responses immediately after receiving the diagnosis of colon cancer**

Immediate mental adjustment responses to diagnosis of colon cancer	
Main categories	Sub-categories
Anxious preoccupation (n=12), P1,5,6,7,11,12,13,14,17,18,19,23	-Difficulty believing, (n=7) P6,7,12,13,17,18,19
	-Anxiety, (n=4) P5,6,19,23
	-Uncertainty, (n=3) P12,14,19
	-Fear, (n=2) P11,14
	-Contact with others, (n=1) P1
	-Seeking information, (n=1)

	P12	
<b>Cognitive fighting spirit (n=9)</b> <b>P1,5,7,12,18,19,23,24,25</b>	<b>-Compulsive confrontation, (n=9)</b> P1,5,7,12,18,19,23,24,25 <b>-Believing positive attitude, (n=2)</b> P1,25	
<b>Active fighting spirit (n=2),</b> <b>P1,23</b>	<b>-Using spirituality, (n=1)</b> P1 <b>- Counting blessings, (n=1)</b> P23	
<b>Hopelessness/helplessness(n=8),</b> <b>P8,11,12,13,14,19,23,24</b>	<b>-At a loss, (n=8)</b> P8,11,12,13,14,19,23,24	
<b>Fatalism (n=1),</b> <b>P15</b>	<b>- Passive acceptance, (n=1)</b> P15	

An ‘**Anxious preoccupation**’ adjustment response was reported by 12 of the 16 participants as their immediate reaction to a diagnosis of colon cancer. All responses related to this response were sub-categorized into “Difficulty believing”, “Anxiety”, “Uncertainty”, “Fear”, “Contact with others” and “Seeking information”.

Most of participants expressed “**Difficulty believing**” through shock and disbelief at the diagnosis of cancer. A few said it felt surreal and it could not happen to them as illustrated in the following quotation:

*When I first found out ... [from] the gastroenterologist [or] whatever you call them, then the very first reaction was I get a bit surreal sort of type thing sort of oh really but it didn't really sink it what it really meant and it wasn't really. (P12)*

*I was shocked, absolutely shocked...Oh emotionally, shocked can't say anything more than that shocked, absolutely shocked...Well disbelief yeah. This sort of thing can't happen to me. (P7)*

For a few participants, “**Anxiety**” was the first reaction after diagnosis of cancer, surgery and lack of information. They described an overwhelming feeling and a stressful time for taking an active role in treatment decisions, which were captured in the following excerpts:

*All these thoughts were just in my head at once I couldn't think straight sort of but I was calm about it... Well I think really it was more mental like, it was like all these thoughts were all, what's that word they say when everything's all mixed up and all joined together at once it's a log jam of thoughts you know I was just walking up, I find I was walking up and down. (P19)*

*Very anxious because I just wanted to have the operation and get it over and done with so that I would know what it was all about and after that they said they'd taken about a foot of the bowel out which that shocked me because I thought it was all of it like and I was very upset. (P6)*

A few responses indicated a sense of ‘**Uncertainty**’ mostly because of the unpredictable nature of cancer. Participants said they did not know much about the prognosis and the future was ambiguous as illustrated by the following quotes:

*Anxious because you didn't know what it really meant and obviously you didn't know how serious the tumour was you know was it, had it gone spread to other parts in my body yeah it just the unknown, not knowing what really it meant.(P12)*

*Oh horrible it's not ever knowing what the real prognosis is going to be is a problem, if the radiation and the chemo work it will shrink the tumour and then we can get an operation and maybe get it cut out again but we [have] just got to wait and see, just got to wait and see. (P14)*

Two participants pointed to ‘**Fear**’ related to all the unknown things which lay ahead. One participant said:

*Very hard to describe how you feel about it. Apprehensive is probably the right word, apprehensive about what the future holds. (P14)*

One participant's ‘Anxious preoccupation’ response took the form of ‘**Contact with others**’ to seek support:

*I rang up a chap who is my mentor, a very good person and he's also into mental health and therapy and such and I cried and I said to him "Today's a shit day" and he said "Fine" and he listened and he was sad on the other end of the phone and I just needed to tell someone that this stinks, this is, I didn't say it was unfair, it's just that it stinks and I'm not happy today and we talked for about half an hour. (P1)*

**'Seeking information'** was mentioned by another participant as a part of 'Anxious preoccupation' response:

*What I did is you know you go on the internet and you start looking at these things and that can be good and bad and I think information is good but it's reading the right information I think is important so overall...I became focused on getting more information and getting in touch with the surgeon and just knowing things. (P12)*

A **'Fighting spirit'** adjustment response was shown by 9 of 16 participants immediately after receiving the diagnosis of colon cancer. The 'Fighting spirit' responses were divided into two sub-categories: **'Cognitive fighting spirit'** including 'compulsive confrontation' and 'Adopting a Positive attitude', and **'Active fighting spirit'** including 'Trying to have a positive attitude by spirituality' and 'Counting blessings'.

Most participants described a confronting coping strategy in response to the diagnosis of colon cancer which was labelled as **'Compulsive confrontation'**. They explained that they had to accept and deal with it and there was no way to undo that. The following excerpts show this response well:

*Oh no cancer fair enough and my mind went I've got it someone else hasn't got it, big deal got to take care of it...immediately that it was a done deal i.e. there was no way that I could undo this. (P1)*

*I was just walking up and down and sort of thinking about it but it hadn't really hit my emotions at that time and I just knew I had to deal with it so I, and yeah...It's very like the earthquakes you have to deal with it but unlike the earthquakes I didn't have moments of feeling absolutely terrified out of my brains but no I just consider you've just got to deal with it. I've got to do. (P19)*

Two participants reported '**Adopting a positive attitude**'; they were satisfied with their own strength to deal with the cancer diagnosis. They said that there was no reason why they could not beat it:

*I've had lots of things wrong with me in my life. I've had four heart attacks and I've beaten everything that's come along. I saw no reason that I wouldn't beat the cancer and I still see no reason that I won't beat it....I don't have any animosity towards cancer. It's an indication that I have something going wrong with me in my life or my body or and I need to work that out. (P25)*

One participant described '**Using spirituality**' as follows:

*I said God got me ready for this and he did [so] because at that point I was at peace, done deal, no worries. (P1)*

Another participant mentioned that he was thankful because he could be in a worse situation which was labelled as '**Counting blessings**':

*But I was aware that I could have been in a lot worse position than what I was with it. (P23)*

Half of the participants explained a '**Hopelessness/helplessness**' response to the diagnosis of colon cancer which was labelled as 'At a loss'. They described feelings of sadness and disappointment when they heard about the cancer. The sense of loss linked to the cancer diagnosis was reported mostly because of unwanted changes in their body and uncertainty about the future. This was captured in the following excerpts:

*Well I don't like the idea of my body; I didn't like the idea of having cancer in my body... I didn't like the thought of having... something horrible and dirty in my body. (P11)*

*It was the same sensation as when someone came and told me that my mother had died. (P19)*

*Just felt very disappointed and that was essentially it; it was just, not something that you really want to hear and no I didn't really want to hear it but I thought "Oh well we'll have to get on and get something done about it"*

*so I wasn't, no I was disappointed and probably a wee bit depressed about it but not a huge amount. (P23)*

One participant reported a '**Fatalism**' response which was labelled as '**Passive acceptance**'. She stated that she was anticipating cancer as her siblings had had it; it had been a bonus to receive the diagnosis when she was over 70 years old. She explained it thus:

*My feeling was quite calm really. I wasn't all that surprised...so I wasn't really surprised that he found something and it wasn't even a shock that it was cancerous. It was just "Well let's move it, yeah"...I have a sister who has had lung cancer and a brother who died of multi cancers when he was 58 so I'm ahead on points over him because I'm 70... Yeah I didn't go into hysterics... (P15)*

### **Awaiting surgery**

At interview one, some of the participants talked about their pre-surgery experience. A few of them reported some level of '**Anxiety**' before surgery. The following excerpts are related to their anxiety:

*I was quite anxious waiting for the op because things were [uncertain]: we might operate first, we might just go ahead and take the cancer out. (P15)*

A '**Compulsive confrontation**' to surgery was reported by some participants before surgery meaning that they had to accept it and get it done. Participants described this response in the following ways:

*Ok well let's get onto it; let's get things happening as soon as possible so that took my mind off it I think. (P12)*

*I'm not a worrier type so it's more I just think well we'll just get on with it and get it done and get it finished. (P15)*

*Very anxious because I just wanted to have the operation and get it over and done with. (P1)*

The '**Surgery information need**' was the response of a few participants. This need was related to uncertainty and unknown issues of the nature and progress of the disease. The participants voiced the following views:

*And eventually I don't know but maybe taken over and spread everywhere don't know, I don't know what the consequences would be when I have extended it yeah so I'm happy with the surgery but the results of the surgery because again I am hoping that only because they take quite a big piece out of your stomach and then pulled it altogether so you know. (P8)*

*Even when I was going into surgery I really wasn't aware of how serious things were. I knew that they were going to do something. (P1)*

*I became focused on getting more information and getting in touch with the surgeon and just knowing things were progressing was actually a really good thing. (P12)*

### **Immediately after surgery in a hospital setting**

Participants described how they felt in hospital immediately after surgery. **'Physical distress'** was reported by 4 of 16 participants immediately after surgery mostly related to catheters, tubes, staples, bandaging and stoma bags. The following illustrates this:

*I wanted certainly like the catheter I wanted out because that was irritating so I monitored myself and every time someone came to me to remove something or do something to me as a plus and it was like this is awesome like and I counted down... but uncomfortable with all the bits connected to me because some of them were pretty sore... the staples and the bandaging and the stoma bag and all this and they're all uncomfortable and there were problems with them and like nothing went easy. (P1)*

**'Difficulties in sleeping'** (n= 2) was the other reported problem immediately after surgery:

*... because of the operation you have to get up quite a lot at night and things like that, do get quite braced off but when the morning comes it's all right again but night time is quite hard sometimes because you're up and down and you've got funny things happening inside you. (P6)*

Most of the participants reported positive emotional responses immediately after surgery. A **'Satisfaction with post-operative care'** was indicated by 5 of 16 participants immediately after the surgery. The following illustrations show this:

*The care that I got at the hospital was excellent. (P12)*

*Everybody was pretty good and everybody's happy with my healing and with the wounds. (P23)*

*The care is absolutely wonderful so you haven't got any worries there. (P6)*

A few participants showed their positive emotional reactions immediately after surgery by '**Confidence in hospital staff**' as evidenced by the following excerpts:

*I brought myself back into I'm in good hands, people are taking care of me... but at any time I wasn't scared and I wasn't angry, I wasn't full of fear, I knew that I was in the right place and whatever was happening someone was going to do it and in any time that I felt a bit of pain or discomfort which was never or there was always someone there to help me so I felt quite good in a way. (P1)*

*But I mean they are doing all they can to get me to come right yeah. (P13)*

Two participants reported '**Anxiety**' immediately after surgery mostly because of catheters and tests during hospitalization. The following excerpts are relevant to this anxiety:

*That was my main problem: the things that they put on you to keep track of what's happening in your body, you know like electronic things all over you and also the regular blood tests that they take and all these things make it not an occasion that you can rest and recover and at a certain stage even I say I came into a panic, nearly a panic stage as if you are drowning because of all the things that... (P8)*

*When I came out of surgery and then found myself in bed with all these things connected to me it didn't quite connect to me but then all of a sudden I realised that there's nothing I can do. You guys have done it all and with my meditation and my peace of mind. (P1)*

## **Post-surgery period, awaiting adjuvant chemotherapy**

A few weeks after surgery, participants had passed their recovery period and were deciding about starting chemotherapy. '**Fitness and activity impairment**' was identified by 6 of 16 participants as the most important problem after surgery which the following passages demonstrate:

*So it certainly has affected me in terms of my fitness and it's impacted on my ability to be more active in sport which I'm active in so that's a bit annoying. (P12)*

*That of course is always a problem - getting up and down stairs and I can't walk for very far for very long, can't sit for too long... Well you know I used to go hunting and shooting and fishing and that sort of thing outdoors and of course I'm not capable of doing that at the moment but hopefully we'll get this behind us and we'll get back to doing some fishing.... (P14)*

'**Tiredness**' was expressed by three of the participants after surgery as the following statements show:

*Still a little bit tired but you know its energy, energy wise is getting better day by day but I'm still not up to what I was, you know. Yeah. (P13)*

*Just the tiredness but its yes I suppose it does a little bit... (P15)*

Three of sixteen participants reported an '**Alterations in bowel elimination pattern**' after surgery as evidenced by the following comments:

*Just getting the bowels working again... They said the bowel went to sleep which meant that it was longer coming back into working order but once I got home I had people help me at home yeah. (P6)*

'**Abdominal pain**' was indicated by three participants as another after effect of surgery. Participants described this problem like this:

*One thing I was getting a bit of a pain in my lower abdomen when I was after walking and so on but I've sort of, I do that and it seems to fix it, must be muscular thing but nothing major. (P19)*

*I suffered with pains in the stomach. Was on medication on pain killers for a while but I haven't been on those for some time. (P7)*

A few weeks after surgery at interview one, 11 of 16 participants showed a '**positive appraisal of surgery and well-being**' as demonstrated by following statements:

*Well the surgery went very well...I've accepted it's been taken away and I'm going to get well. (P11)*

*Oh no real problems... Other than that pretty normal run of events I think. I feel pretty well, there's no major complications just a matter of progress over time that is what I'm told. (P23)*

*Well I'm happy with the result because of what it can do? When I wouldn't have done it? Yeah so with the tumours it caused me so much pain and now I'm not having the pain any more. (P8)*

Five of 16 participants were satisfied with the surgical experience and recovery process, categorized as an '**Appraisal of progressive recovery**', as evidenced by the following:

*My recovery was actually quite quick and I was back at work within sort of three weeks so overall yeah my experience was actually very good ...also been relatively fit so I think that contributed to recovery quite quickly so it was overall a reasonably good experience as far as surgery goes. (P12)*

*I had no complications nothing and every time they said it's beautiful how it's healed and I am also happy at the way the recovery went. (P8)*

Participants described how they were adapting after surgery when they were about to decide on the next stage of treatment: adjuvant chemotherapy. '**Fighting spirit**', '**Anxious preoccupation**', '**Hopelessness/helplessness**' and '**Fatalism**' were reported as the most frequent adjustment responses at this stage (Table 4.3).

**Table 4.3: Mental adjustment responses to colon cancer after surgery**

Mental adjustment to colon cancer after surgery	
Main categories	Sub-categories
<b>Cognitive fighting spirit, (n=11)</b>  <b>P1,5,8,11,13,14,17,19,23,24,25</b>	<b>-Determined to fight illness, (n=4)</b>  P13,17,24,25  <b>- Using spirituality, (n=4)</b>  P8,11,14,19  <b>-Keeping busy, (n=3)</b>  P1,5,17  <b>-Counting blessings, (n=2)</b>

	<p>P19,15</p> <p><b>-Humour, (n=2)</b></p> <p>P1,23</p>
<p><b>Active fighting spirit, (n=10)</b></p> <p><b>P6,8,11,13,14,17,18,19,24,25</b></p>	<p><b>- Adopting positive attitude, (n=6)</b></p> <p>P11,13,17,18,19,25</p> <p><b>- Compulsive confrontation, (n=5)</b></p> <p>P5,6,8,9,24</p> <p><b>-As a challenge, (n=3)</b></p> <p>P14,24,25</p>
<p><b>Anxious preoccupation, (n=7)</b></p> <p><b>P1,8,12,14,18,19,24</b></p>	<p><b>-Uncertainty, (n=5)</b></p> <p>P1,8,12,18,19</p> <p><b>-Preventing plans, (n=4)</b></p> <p>P8,14,18,24</p> <p><b>-Seeking information, (n=2)</b></p> <p>P1,8</p> <p><b>-Anger, (n=1)</b></p> <p>P19</p>
<p><b>Hopelessness/helplessness, (n=6)</b></p> <p><b>P1,6,8,18,19,24</b></p>	<p><b>-At a loss, (n=6)</b></p> <p>P1,6,8,18,19,24</p>
<p><b>Fatalism, (n=5)</b></p> <p><b>P8,7,15,17,19</b></p>	<p><b>-Taking one day at a time, (n=4)</b></p> <p>P7,15,17,19</p> <p><b>-In hands of God, (n=2)</b></p> <p>P8,17</p> <p><b>- Left all to doctors, (n=1)</b></p> <p>P17</p> <p><b>-Fatalistic, (n=1)</b></p> <p>P8</p>

**‘Fighting spirit’** responses were reported by the most participants post-surgery. This response was sub-categorized as **‘Active fighting spirit’** including ‘Determined to fight illness’, ‘Using spirituality’, ‘Keeping busy’, ‘Counting blessings’, ‘Humour’ and **‘Cognitive fighting spirit’** including ‘Adopting Positive attitude’, ‘Compulsive confrontation’ and ‘At a challenge’.

Some participants mentioned that they were fighting cancer and intended to beat the disease; that was labelled as **‘Determined to fight illness’** and was demonstrated in the following comments:

*I’m determined I’m going to recover...I’m pig headed, optimistic, determined to beat it. (P17)*

*I want to say I’m going to beat this, this is what I intend to do and I’m going to beat it whereas the doctors say well. (P25)*

**‘Using spirituality’** was described by some of participants as a way to fight cancer. They were trying to use the power of spirituality to overcome disease. They explained it thus:

*I’m a Christian and I’m going to be fine... And the strength of prayer that’s a big thing and of course well I know there are some believers so this also helps. (P11)*

*What I believe is right or wrong you know because I do believe that he has shown me something that would help mankind to live differently not that we kill each other but that we care for each other yeah and that is really what my spiritual battle was. (P8)*

A few participants said that they were **‘Keeping busy’** themselves with treatments, follow ups and other activities; so they did not have time to think about cancer. These excerpts explain how they did that:

*I guess I kept my mind busy ... there was always something uncomfortable that I was waiting to get fixed so I never focused on cancer and I still don’t focus on it. (P1)*

*Well there’s nothing I can do about it so I have to get on and that’s it...I haven’t thought much about the cancer actually seeing I’ve got this like the learning to walk and I go for walks two or three days a week with the Cross*

*ladies.. Oh just went out walking and talked to people on the phone and people come in. (P3)*

Two participants reported **‘Counting blessings’** by reminding themselves how lucky they were not to be in a worse situation. They stated:

*I just feel very grateful that I wasn't born on the pavement in Calcutta, I just feel very grateful and there's all these expert people like you know all along the way from the doctors to the nurses and they've got all these skills...(P19)*

*And felt I was probably luckier than some because I didn't have a bag. I was just me and once I came out of hospital I could eat normally. (P5)*

Two other participants said that a sense of **‘Humour’** helped them to adapt and fight cancer in a better way. They said:

*The result is I still have a sense of humour, that hasn't killed me that one. (P1)*

*What I'm told and it's thought being cheeky I said to them "I'll be right in a few days" and they all sort of looked at me and sort of laughed I think and said "You'll be weeks more than days" which I knew that it would be really but just sort of have to have a bit of humour in the whole thing. (P23)*

Many participants described **‘Adopting a positive attitude toward disease’** which might help to cope with it. They shared this response by saying:

*What else, I'm still mobile yeah, I might not be able to do or go where I want to but I do my best. (P18)*

*Well it's just a bugger that I got it really that's all I can say really, but I mean they are doing all them can to get me to come right yeah... No I haven't accepted death no, I'm not looking that way; no way...It's not the end of the world. (P13)*

**‘Compulsive confrontation’** was reported by some of participants which meant that they had actively accepted cancer and intended to adjust to it. This adjustment response was captured in following comments:

*I mean it's something you've got to accept, can't do much about it. (P5)*

*Yeah I have to fight and that is what I'm working on, I have to try to come back and to the routine of life, I want to get back to that and then also we have a business that I have to do the administration yeah so I've started it, so yeah I have to really convince myself that I have to. (P8)*

A few participants explained this situation '**As a challenge**' which is an inevitable part of life to deal with. They described their experience in this way:

*Yeah it's happened and life is a game of cards and you play the hand you get dealt, that's all you can do; you've just to go to your best for like you can do yeah. (P14)*

*Well I used to be a farmer and yeah we had our ups and downs and there was always something you think you're going along good and yeah something would come along and give you a good kick up the backside and yeah it's part of life. I've had to work with it so this is just another bit of a challenge yeah. (P24)*

'**Anxious preoccupation**' was the second mental adjustment response to colon cancer after surgery. It was sub-categorized as 'Uncertainty', 'Preventing plans', 'Seeking information' and 'Anger'.

Some participants reported living with '**Uncertainty**' related to unknown aspects of the disease. They described their life as insecure and unpredictable because they did not know what their future held as the following remarks show:

*I don't know what the process is going to be with my body and this particular thing... (P1)*

*I don't know what it's like basically... think well what I could be doing or what hopefully I might be able to do later on... Oh I don't know that's out of my control basically. My future yeah, no I'm going to wait. (P18)*

Some others expressed the view that cancer was '**Preventing plans**' because it had changed their way of life and had become their main preoccupation. They said:

*I could see it's going to change my way of life, I wasn't be able to do probably the things I had planned to do and I'm still working on that so there will be things now that probably I won't do. (P18)*

*Well at this stage in my life I haven't got a great deal of goals, a goal of course is to... Well the main goal is to get through this cancer. (P14)*

Two participants were '**Seeking information**' about an uncertain future. One participant said this:

*So I'm off the rocking horse I'm leaving it up to you guys, you tell me what's going on, I believe you, you may tell me lies I don't know but that's all right. (P1)*

One participant reported '**Anger**' towards her doctor who did not do a colonoscopy after the blood test a couple of years before to rule out cancer. She explained:

*I was a bit annoyed with my doctor for not driving this because I ended up driving it more but I went and told him because I've known him for many years and that was the first thing I felt was resentment towards him that I had actually gone back to him and said how about a colonoscopy and I felt he should have done that after some blood tests he sent me for came back negative but even at the time of the colonoscopy I knew that cancer was a possibility but I ruled it out, not out of denial but because there's just no cancer in the family. (P19)*

Some participants described their mental adjustment response as '**At a loss**' in the '**Hopelessness/helplessness**' category. They expressed a pessimistic attitude toward the future over which they had no control. They shared their feelings as follows:

*Well I feel it's probably the worst disease you can get analysed with or the one most people know about...I did want to sort of shout "Shit I've got cancer!" That sort of thing, how did I get it, yeah? (P6)*

*Not happy about the future but I can't do anything about it so just got to get on with life yeah... I'm going to get worse so how I adjust then that will be a different story...Yeah I'm going to get worse and worse yeah...it's going to be a bit hard to handle but yeah, I can't get about and do things yeah it's you know it's going to affect me all right, yeah. (P24)*

A few participants showed a '**Fatalism**' adjustment response towards cancer after surgery. The relevant responses were sub-categorized as 'Taking one day at a time', 'In the hands of God', 'Left all to doctors' and 'Fatalistic'.

Some participants reported '**Taking one day at a time**' in order to stop worrying about the future. They were trying not to overwhelm themselves or miss the present moment. The following excerpts show this response well:

*One day at a time. If I looked at the whole thing you know like right out well I don't think that's such a great idea. I mean I've got an idea where I'm going with it... No, not really; I try and take one day at a time. (P19)*

*I just live day to day you know and I just don't think about it. It's you know getting over the operation. I got over that and then I just move on, I don't sit and think about what's happened or I just try and live day to day and get on with it. (P7)*

A '**In the hands of God**' response was reported by two participants as a way of adjusting to colon cancer after surgery. One participant said:

*Yeah I believe, yeah I'm a believer in God made us, created us and in my belief yeah we say that God can do everything yeah and if it is His will He can heal you yeah but it comes down to faith... Faith means that you trust, that you depend yeah so I depend on my health on my God yeah and you know there's a person that's has come here to this planet to tell us all this yeah and it is the God Jesus Christ for us yeah, and He has healed many people in His time... here. (P8)*

One participant said that he has '**Left all to doctors**' to cope with it. He explained:

*Well it's all in the hands of the God, isn't it, yes? And the surgeons yes... (P17)*

Another participant showed a '**Fatalistic**' attitude toward cancer by this statement:

*I had the attitude let it all happen and see where it leads to. (P8)*

**Mental adjustment to cancer and self-efficacy:** As Bandura (1997) highlighted, self-efficacy shows confidence in an ability to perform a task or behaviour. Through this definition participants' responses were categorized as high to moderate and low self-efficacy groups.

Eleven of 16 participants were categorized as a moderate to high self-efficacy group who showed belief in inner strength and confidence to cope with new situations. This group believed in their power to control the situation and reported that they were able to face up to and deal with life's challenges. These perceptions were captured in following comments:

*I am quite a strong person...I really do, I really do believe in myself and I think it's also why it is that I've kept myself fit and active and led a good life and I also have God you know. (P11)*

*Yes I'm actually a reasonably confident person so I've always been quite successful...I think I've got a very good mind-set to be able to cope with those sorts of things...I'm a positive sort of person. (P12)*

*I'll manage yeah...Well I used to be a farmer and yeah we had our ups and downs and there was always something you think you're going along good and yeah something would come along and give you a good kick up the backside and yeah it's part of life. I've had to work with it so this is just another bit of a challenge yeah. (P24)*

*I'm pretty tough but I think probably the word is probably resilient, I feel I'm very resilient...just a matter of you know take each day and hopefully it all comes right and so far it all has yeah. (P15)*

Low self-efficacy perception was reported by 5 of 16 participants. They tended to believe that it was a tough situation which they might not be able to handle. They mentioned it was hard to adapt to new situations and they would not manage this challenge without the power of God or spirituality. They stated:

*There's things I'd like to do but I can't...it's taken me years to say that but now I accept that I'm sort of accepting myself and accepting of my limitations...I'm sort of spiritual I suppose and I think spiritual things are everywhere. (P19)*

*I'd never be able to handle it... I just didn't realise how strong I was confronting this and...I got strength from where I never thought I had strength before so, God only knows where that comes from. (P1)*

*Well you know the stoma bag is new and I have difficulty to handle it...Believing means for me ... it's a subconscious revelation that you put in practice yeah I believe that there is a Creator...so believing in myself means that I have a subconscious revelation of myself and the only subconscious revelation of myself is my mission because I can't prove that it's true or not true yeah. (P8)*

*I feel everybody feels sorry for me at the moment. I don't know why I feel like that ... feeling inside of me that's nothing to do with it... (P6)*

Participants' mental adjustment responses in the moderate to high self-efficacy group were compared with responses in the low self-efficacy group to find out how mental adjustment to cancer correlated with perceived self-efficacy (Table 4.4).

**Table 4.4: Mental adjustment responses to colon cancer after surgery by self-efficacy responses**

Group	High to moderate self-efficacy N=11	Low self-efficacy N=5
<b>Mental adjustment to cancer responses after surgery</b>	<b>Active fighting spirit, (n=8)</b> P5,11,13,14,17,23,24,25,	<b>Hopelessness/helplessness, (n=5)</b> P1,6,8,18,19
	<b>Cognitive fighting spirit, (n=6)</b> P11,13,14,17,24,25	<b>Anxious preoccupation, (n=4)</b> P1,8,18,19
	<b>Fatalism, (n=3)</b> P7,15,17	<b>Cognitive fighting spirit, (n=3)</b> P6,8,18
	<b>Anxious preoccupation, (n=2)</b> P12,14	<b>Active coping spirit, (n=3)</b> P1,8,19
	<b>Hopelessness/helplessness, (n=1)</b> P24	<b>Fatalism, (n=2)</b> P8,19

Participants in moderate to high self-efficacy group reported more active adjustment styles like 'Fighting spirit' and less 'Anxious preoccupation' and 'Hopelessness/helplessness' after surgery. 8 of 11 participants showed the 'Active fighting spirit' response and stated that they

were determined to fight the illness and were trying to keep themselves busy with treatments, follow ups and other activities. Adopting a positive attitude toward disease through spirituality and using humour were the other responses. 'Cognitive fighting spirit' were reported by 6 of 11 participants in the moderate to high self-efficacy group evidenced by responses such as believing in a positive attitude. They explained that they should confront the disease and were dealing with it as a challenge.

Conversely, 'Hopelessness/helplessness' and 'Anxious preoccupation' were the most common mental adjustment responses among participants in the low self-efficacy group. 'Hopelessness/helplessness' reported by all of these participants was described as feeling at a loss. The 'Anxious preoccupation' mental adjustment response was shown by 4 of 5 participants in the low self-efficacy group. All of them expressed uncertainty regarding the nature of the disease and their future. Cancer was reported as a barrier to planning for the future by these participants.

**Mental adjustment to cancer and self-regulation:** Participants talked about how they perceived, planned and changed their behaviours through the process of self-regulation in their cancer journey. Responses of 5 of 16 participants were categorized as '**Task perception and goal setting**'. They described their experience as a new task which they had to deal with it and said they would benefit from being optimistic about it. They explained that the main goal was to get over the cancer and they looked forward to getting back to normal life as the following comments attest:

*I would yeah you put a new task in front of me, let me go through the anxiety period, if I can't do it, if it's too tough, it's too hard, then by the time I've done the process I'm in there but I think that's just normal with everybody you know. It's like starting anything new. (P1)*

*Well at this stage in my life I haven't got a great deal of goals, a goal of course is to... Well the main goal is to get through this cancer. (P14)*

Six of 16 participants' responses were categorized as '**Enacting**' which described how they were trying to adjust to the life-changing experience of cancer. They stated that they had to stop their usual and leisure activities, wait for treatments and get help with their primary needs, but they coped with those because it was going to improve. Their attitude was captured in these excerpts:

*I've already done that because I was in a dance group... and I stopped that prior to my operation... and so I have made an adjustment there...it was a big decision to make because I love going out...I think well perhaps it was my time anyway to move on from the dancing but I still do the marching for exercise and I'm meeting other women and we have a lot of fun. (P11)*

*...this year wasn't you know wasn't on my plan to be hanging around hospitals and waiting for treatment...I'm not ill, I'm not disabled in any way so my life once I walk out of here... I tend to think I'm sure it's working. (P15)*

Five of 16 participants showed some kind of a '**Self-regulation difficulty**' by reporting not being happy with life changes after receiving the diagnosis of cancer. They explained that it was not easy to stop usual activities, withdraw from their jobs and stick to treatments. Two participants stated:

*Well I'm not doing anything. I've done nothing for six months... Well I've been basically farming and engineering all my life and my recent job was with farming and restoring machinery... I get bored, no I get bored but there are things you know when I can get out a bit more there will be things I will pick up. (P18)*

*Well I think here I've had to give the teaching away and crawl down to the work and income... and it's hard with \$200 a week. (P19)*

One participant said that he was just focused on his religious beliefs and he refused a blood transfusion and chemotherapy. He explained it like this:

*I think you should not be flexible when you want to achieve your goals. People tried to convince me that a blood transfusion would be good yeah and they want , the surgeon really tried to push it on me but I was focused yeah I said "No I can't do that because it's my belief." (P8)*

Participants' mental adjustment to cancer responses after surgery were compared with their self-regulation responses (Table 4.5).

**Table 4.5: Mental adjustment responses to colon cancer after surgery by self-regulation responses**

Self-regulation response	Task perception and goal setting N=5	Enacting self-regulation N=6	Self-regulation difficulty N=5
<b>Mental adjustment to cancer after surgery</b>	<p><b>Active fighting spirit, (n=4)</b> P1,13,14,23,</p> <p><b>Anxious preoccupation, (n=3)</b> P1,12,14</p> <p><b>Cognitive fighting spirit, (n=2)</b> P13,14</p> <p><b>Hopelessness/helplessness, (n=1)</b> P1,</p>	<p><b>Active fighting spirit, (n=4)</b> P5,11,17,25,</p> <p><b>Cognitive fighting spirit, (n=4)</b> P5,11,17,25,</p> <p><b>Fatalism, (n=3)</b> P7,15,17,</p>	<p><b>Hopelessness/helplessness, (n=5)</b> P6,8,18,19,24</p> <p><b>Cognitive fighting spirit, (n=5)</b> P6,8,18,19,24</p> <p><b>Anxious preoccupation, (n=4)</b> P8,18,19,24</p> <p><b>Active fighting spirit, (n=3)</b> P8,19,24</p> <p><b>Fatalism, (n=2)</b> P8,19</p>

Participants who showed task perception and goal setting as their self-regulation response reported ‘Active fighting spirit’ and "Anxious preoccupation" as the most common mental adjustment responses after surgery. ‘Fighting spirit’ was the most common response for participants with an enacting self-regulation response while none of participants reported ‘Anxious preoccupation’ and ‘Hopelessness/helplessness’ responses. Conversely; ‘Hopelessness/helplessness’, ‘Cognitive fighting spirit’ and ‘Anxious preoccupation’ were most frequent for participants with self-regulation difficulties.

**Mental adjustment to cancer and outcome expectations:** In socio-cognitive theory the consequence of an action is called ‘outcome expectancy’ and through this question, participants assessed their cancer experience and explained what they expected in future. Nine of 16 participants reported a positive ‘**optimistic**’ attitude toward treatment and they were hopeful about the future. They pointed out that optimism was their own choice and there was no advantage in being negative about the future. One participant said:

*I think you have to be positive you know, it's no good being negative and it just drags you down so... I'm looking forward to getting this year over with, getting past all the chemo and then we can move on and start planning some more holidays yeah. (P7)*

Some participants explained that they were determined to recover by being optimistic about the future. They stated that they had many future plans and they were not going to give up as the following passages show:

*I'm always optimistic yeah, when I reach 100, no? I've done everything that I've ever wanted to do. There are a million things I still want to do and I do know that even if I live to 120 I still wouldn't get done everything that I want to get done. (P25)*

*I'm determined I'm going to recover... Oh optimistic I think if we can keep on top of this there's no reason why I can't go on for a hundred years. There's not a hundred years, fifty but yeah I mean there's no point in being pessimistic about it too much. (P23)*

Seven of 16 participants used “**Uncertainty**” to describe the future. They were concerned about a recurrence of cancer after treatment ended. They reported how long they were going to live was beyond their control and even during remission it would always be uncertain about what might or might not happen. These feelings are well described in the following excerpts:

*You don't know how long you're going to live. They can give you a prognosis; if things turn to custard and they say "Well you know" but who knows they can say give you six months and you step outside the next day and a bus hits you. (P15)*

*Oh I don't know that's out of my control basically. My future yeah, no I'm going to wait... I'm just waiting for that day to say look I can do that or whatever. (P18)*

*But I can only find total peace when I really see how it will evolve in my future life. (P8)*

A comparison of mental adjustment to cancer post-surgery responses between optimistic and uncertain participants was made to find out how outcome expectations correlated with mental adjustment to cancer after surgery (Table 4.6).

**Table 4.6: Mental adjustment responses to colon cancer after surgery by outcome expectations responses**

Outcome expectations	Optimistic (n=9)	Uncertain (n=7)
Mental adjustment to cancer after surgery	<b>Active fighting spirit, (n=7)</b> P5,11,13,14,17,23,25	<b>Anxious preoccupation, (n=6)</b> P1,8,12,18,19,24
	<b>Cognitive fighting spirit, (n=6)</b> P6,11,13,14,17,25	<b>Hopelessness/helplessness, (n=5)</b> P1,8,18,19,24
	<b>Fatalism, (n=2)</b> P7,17	<b>Active fighting spirit, (n=4)</b> P1,8,19,24
	<b>Anxious preoccupation, (n=1)</b> P14	<b>Cognitive fighting spirit, (n=4)</b> P8,18,19,24
	<b>Hopelessness/helplessness, (n=1)</b> P6	<b>Fatalism, (n=3)</b> P8,15,19

Participants who reported optimistic attitudes towards the future and expected to return to good health showed ‘Active fighting spirit’ and ‘Cognitive fighting spirit’ as the most common mental adjustment responses after surgery. It seems that participants who were determined to recover and felt positive about treatment consequences chose to fight cancer and they were more engaged in active coping styles.

Conversely, participants feeling uncertain about the future responded mostly with ‘Anxious preoccupation’ and ‘Hopelessness/helplessness’ responses after surgery. Living with uncertainty led to apprehension and the disease was seen as a major threat. For these participants uncertainty over the control of the disease met with the response of feeling at a loss.

**Mental adjustment to cancer and social support:** Socio-cognitive theory believes that social environment is a factor affecting the behaviour and it can be described as family members,

friends and colleagues (Bandura, 2001). Participants' responses about their social networks were categorized as high and low perceived social support and based on marital status and living alone or with family; four groups were created: **high perceived social support, married and living with family** (n=8), **high perceived social support and living alone** (n=3), **low perceived social support and living alone** (n=3) and **low perceived social support, married and living with family** (n=2).

Participants who reported high perceived social support describe social connections (marriage, friendship or membership of religious groups) as helpful in managing their new situation. Support from partners, family and friends was effective and beneficial in terms of empathy and caring, offering service or even companionship. The following passages show participants' high perception of social support:

*Well I think what's helped me is having the support of my friends and my church family, they have been absolutely wonderful and they ring up and they pop in, they've brought food in that was really wonderful and we've got home help because my husband... [is] coming up 83 this year and he was doing for me and then I thought well he's going to get very tired you know by the time you know I recover but anyway so we've had home help and that's been a great thing too. (P11)*

*Oh yeah they've always been there to support me. My daughter, my partner and yeah I've always had family around me so it's been good support. (P7)*

Participants who expressed a perception of low social support mentioned that they did not want others to get emotionally involved with their disease. They said that family were too busy to help and they felt they should not bother them. A few participants reported some kind of family problem like a family member with cancer or some other illness which was their priority. A few participants expressed the view that everybody felt sorry for them which made them feel down. The following excerpts describe this perception of social support:

*No the lady I live with I've known for about 40 years but we're not in a romantic relationship or in a supportive relationship... I've kept her close to what's going on but not in the crying emotional support information. (P1)*

*Yeah they're not very happy. There have been a few tears... but she's had a bad run too [as] she's had cancer once herself... She had [it] down below*

*and then ... years after the operation she's had to go to a bag and all that now yeah so she's had it all herself. (P24)*

*I feel everybody feels sorry for me at the moment. I don't know why I feel like that but you feel as though other people are talking about she's got cancer like it's contagious but it's just a funny feeling inside of me that's nothing to do with ... when people ring up I can be feeling quite down... I've got my husband's short term heart failure so I really feel as if my priority is him and I don't really think about myself. (P6)*

A comparison of mental adjustment to cancer responses after surgery among four groups aimed to find out how mental adjustment to colon cancer was correlated to social support. (Table 4.7).

**Table 4.7: Mental adjustment responses to colon cancer after surgery by social support status**

Social support status	Mental adjustment after surgery	
<b>High perceived social support, married and living with family, (n=8)</b>  P5,7,8,11,12,13,14,25	-Active fighting spirit, (n=7)  P5,8,11,13,14,17,25	
	-Cognitive fighting spirit, (n=5)  P8,11,13,14,25	
	-Anxious preoccupation, (n=3)  P8,12,14	
	-Fatalism, (n=3)  P7,15,17	
	-Hopelessness/helplessness, (n=1)  P8	
	<b>High perceived social support, living alone, (n=3)</b>  P15,17,23	-Active fighting spirit, (n=2)  P17,23
	-Fatalism, (n=2)  P15,17	
	-Cognitive fighting spirit, (n=1)  P17	

<b>Low perceived social support and living alone, (n=3)</b>	-Anxious preoccupation, (n=3)
<b>P1,18,19</b>	P1,18,19
	-Hopelessness/helplessness, (n=3)
	P1,18,19
	-Active fighting spirit, (n=2)
	P1,19
	-Cognitive fighting spirit, (n=2)
	P18,19
<b>Low perceived social support, married and living with family, (n=2)</b>	Active fighting spirit, (n=2)
<b>P6,24</b>	P6,24
	-Cognitive fighting spirit, (n=2)
	P6,24
	-Anxious preoccupation, (n=2)
	P6,24
	-Hopelessness/helplessness, (n=2)
	P6,24

Most high perceived social support participants were married and living with their family. They reported ‘Active fighting spirit’ and ‘Cognitive fighting spirit’ as the most common mental adjustment responses after surgery. Few participants who showed high perceived social support were living alone and most of them reported ‘Active fighting spirit’ and ‘Fatalism’ responses to adjust to cancer. Conversely, ‘Anxious preoccupation’ and ‘Hopelessness/helplessness’ responses were found among all the participants with low perceived social support who were living alone. All the participants with low perceived social support who were married and living with their family reported ‘Fighting spirit’, ‘Anxious preoccupation’ and ‘Hopelessness/helplessness’ as their mental adjustment responses after surgery.

### **Post-chemotherapy period, 4-6 months after surgery**

Twelve participants took part in stage-two interviews 4-6 months after surgery. Nine of them reported that they had completed chemotherapy. One of the participants refused to receive

chemotherapy because of religious convictions and two others had to stop chemotherapy because of toxicity issues.

Fatigue was reported by 7 of 12 participants as the most common problem during and after chemotherapy. They described it as lacking in energy to do activities normal before having cancer. They explained it thus:

*...the main problem is feeling fatigue which is different from feeling tired. You sort of lack energy and like for example, a couple of days ago I thought I'll walk up the hill, because I normally do when I haven't got cancer, and I could only get half way up .When I came down my legs were all shaky because it's just an energy thing. (P19)*

*I'm still very tired ...it takes about a year sometimes for it to get out of your system but I don't know. I've started walking and things like that my energy is sloped really bad. (P6)*

Coldness of hands and feet, nausea, bad taste in the mouth and diarrhoea were each reported by one participant.

At this stage, ‘**Cognitive fighting spirit**’ and ‘**Fatalism**’ were the most common mental adjustment responses whereas ‘Active fighting spirit’ was least common (Table 4.8).

**Table 4.8: Mental adjustment responses to colon cancer 4-6 months after surgery**

Mental adjustment responses to colon cancer 4-6 months after surgery	
Main categories	Sub-categories
<b>Cognitive fighting spirit, (n=6)</b> P6,7,8,13,19,23	<b>-Compulsive confrontation, (n=5)</b> P7,8,13,19,23
	<b>-Adopting positive attitudes, (n=4)</b> P6,7,8,19
	<b>-At a challenge, (n=2)</b> P19,23
<b>Fatalism, (n=5)</b> P1,5,8,14,15	<b>-Passive acceptance, (n=4)</b> P1,5,14,15

	<p><b>-Fatalistic, (n=2)</b></p> <p>P8,14</p>
<p><b>Anxious preoccupation, (n=4)</b></p> <p>P1,12,19,23</p>	<p><b>-Uncertainty, (n=4)</b></p> <p>P1,12,19,23</p>
<p><b>Hopelessness/helplessness, (n=4)</b></p> <p>P5,8,11,14</p>	<p><b>-At a loss, (n=4)</b></p> <p>P5,8,11,14</p>
<p><b>Active fighting spirit, (n=3)</b></p> <p>P1,5,11</p>	<p><b>-Trying positive attitudes, (n=2)</b></p> <p>P1,5</p> <p><b>-Keeping busy, (n=1)</b></p> <p>P11</p> <p><b>-Using spirituality, (n=1)</b></p> <p>P1</p> <p><b>-Fighting illness, (n=1)</b></p> <p>P1</p>

The ‘**Cognitive fighting spirit**’ response reported by half the participants included ‘Compulsive confrontation’, ‘Believing in positive attitudes’ and ‘At a challenge’.

Some participants explained their ‘**Compulsive confrontation**’ response as having to deal with cancer and trying to adjust to it as the following comments reveal:

*Well it's again; you just got to deal with it, got to recognise the fact that something's happened and you need to just adjust to it, you need to make adjustments and hopefully for the better such as wanting to get back to work rather than sit at home and, how much more have you got to do, you've got pages of it. (P23)*

*I think things are getting because I had to get used to having a piece taken out, have to get used to a stoma bag and have to get used to the flap that they put in, it's still a wee gap where food comes out. (P8)*

The ‘**Believing in positive attitudes**’ response was reported by few participants. They believed that they were coping well and that they recovered after receiving chemotherapy. The following excerpts explain this response:

*I think I'm coping really well with it, if you don't mind my saying so. I think as well as anybody could. And I think that's because I'm 62 and I've had quite a bit of life experience and I think that makes a difference. (P19)*

*No I feel as if I've fully recovered. I really feel I have to but I haven't got any signs of any cancer. (P6)*

Two participants described cancer '**At a challenge**' which is a normal part of life. One participant said:

*I think cancer is another of life's challenges for me. Much like the earthquakes were. You've simply got to deal with it step by step and day by day. (P19)*

A '**Fatalism**' response by 5 of 12 participants was sub-categorized as 'Passive acceptance' and 'Fatalistic' responses.

A few participants explained that they had accepted cancer but not as an important part of their lives; nothing could change it and there was nothing they could do about it. These responses labelled as '**Passive acceptance**' were captured in the following excerpts:

*Well nothing's going to change of course. I mean ultimately it will come to a conclusion and I don't feel any different about that. I know what's going to happen in the finish and yeah. Do I feel any different? No, not really. I just wish the discomfort wasn't as bad. (P14)*

Two participants showed '**Fatalistic**' attitudes towards their new situation. One participant believed that this new situation would come to a conclusion and he could not have any control over it. The other participant explained that cancer was a curse and he could not stop it.

*No I think it has to do with my religion. Cancer is a curse we say not a blessing yeah so if you go...you know you're cursed, who I to stop it am. (P8)*

The '**Anxious preoccupation**' response was common to 4 of 12 participants in the form of "**Uncertainty**" about the future. This response can be seen in the following excerpts:

*No, I do have the knowledge that I've got a bit of uncertainty. I have to talk to them about this because I don't know what they do, if they have some way*

*of measuring the effectiveness of the chemotherapy or if they just hope like hell that it's killed a few more cancer cells, but I'll have to live with uncertainty... I'm just getting used to that idea that I'll have to live with uncertainty. I don't know if it will come back and I don't know if they've got all the cancer. (P19)*

*I'm not living in this, it doesn't exist. It's inside me; it may grow, it may never grow again. I don't know. I'm hoping that it doesn't grow again but if you guys say to me in two years, five years or six months it's come back... (P1)*

Four of 12 participants expressed a '**Hopelessness/helplessness**' response which was sub-categorized as '**At a loss**'. They described how talking about cancer got them emotional and it was terrible to change their previous active lifestyle. One participant pointed to cancer as a kind of disability. They explained it in this way:

*Well, I seem to be coping but God must be giving me the strength because that's...well now I'm talking about it, that's when I get a bit emotional I think. (P11)*

*It's a horrible damn thing. It's the last thing one would ever expect. Especially in my lifestyle as it was, very active, outdoors and all that sort of thing and you realise that all that's now behind you. That's a bit of not upsetting but it's a well yeah it is upsetting I suppose yeah. (P14)*

*... I say the only problem I have is that I feel handicapped, I feel not as a normal person yeah, a normal person can go normally... (P8)*

'**Active fighting spirit**' was the least common mental adjustment response for to six months after surgery. This response was sub-categorized as 'Adopting positive attitudes', 'Keeping busy', 'Using spirituality' and 'Fighting illness'.

A few participants described how they were trying to be positive and deal with cancer as a normal part of life. Their responses were labelled as '**Trying to adopt positive attitudes**'. One participant said:

*While, hopefully I focus on positive things and want to do things. I used to always help other people all the time and I want to get back to doing that and*

*I do it if I can. I'm on the phone talking to people and yeah trying to be as positive as I can. (P5)*

One participant justified a '**Keeping busy**' response by stating that it was a very useful way to avoid thinking about cancer. She said:

*Well I think so because I keep myself busy. Well that could be a cover up couldn't it? But I'm energetic and it's a funny thing, when I'm busy doing things I don't think of myself. (P11)*

'**Using spirituality**' was resorted to by one participant who said:

*So you know a situation comes up and it's difficult; either I can deal with it or I leave it alone. And this is one of the ones that I had to deal with, so I dealt with it on a spiritual basis. (P1)*

This participant stated that he was ready even for another round of surgery or chemotherapy to '**Fight illness**':

*If it's there and you guys say to me we can do a surgery or a chemo, I'm up for it. Yeah I want to be on this planet for as long as I can. (P1)*

**Mental adjustment to cancer and self-efficacy:** In line with socio-cognitive theory, 6 of 12 participants expressed a moderate to high self-efficacy response. They believed that they were mentally strong enough to handle new situations. They said that they were trying hard to get back to normal and getting over it. The following statements show some moderate to high self-efficacy responses:

*Yeah I feel I'm quite strong and getting over it all and just want to get back to normal and trying very hard to get back to normal. (P6)*

*So my personality is very positive... so always an optimistic type person, who faces challenges head on. (P12)*

*Yes, I'm an extrovert and I'm a fairly strong personality. I've done quite a bit of sort of shall we say spiritual work and so I think that really helps me, because I see this as a process and one I'm going to get through and that's how I do my life really. (P19)*

A low self-efficacy response was shown by 6 of 12 participants. They explained that they were unable to change anything about their new situation and they just carried on with life as the following excerpts show:

*I can't do anything about it apart from what you tell me to do. And if you don't tell me to do anything I just carry on doing my life. I handed it over to you. So that's how I deal with it. (P1)*

*I feel that I'm not coping... I probably couldn't do anything to help with the state that I'm in, the stage I'm at, but it would be nice to know what is going on. (P5)*

*I accept the realisation that it's there. There is nothing I can do about it. It's a horrible damn thing. It's the last thing one would ever expect. Especially in my lifestyle as it was, very active, outdoors and all that sort of thing and you realise that all that's now behind you. (P14)*

Participants' mental adjustment responses in the moderate to high self-efficacy group were compared with responses in the low self-efficacy group to find out how mental adjustment to cancer correlated with perceived self-efficacy (Table 4.9).

**Table 4.9: Mental adjustment responses to colon cancer 4-6 months after surgery by self-efficacy responses**

Group	High to moderate self-efficacy	Low self-efficacy
Mental adjustment to cancer responses after surgery	Cognitive fighting spirit, (n=5) P6,7,13,19,23	Fatalism, (n=5) P1,5,8,14,15
	Anxious preoccupation, (n=3) P12,19,23	Hopelessness/helplessness, (n=4) P5,8,11,14
		Active fighting spirit, (n=3) P1,5,11
		Anxious preoccupation, (n=1) P1

The ‘Cognitive fighting spirit’ response was manifested in 5 out of 6 participants in the moderate to high self-efficacy group. They said that they had to face their new situation as a challenge. A positive attitude to this new situation was described as helpful by this group.

For the low self-efficacy group ‘Fatalism’ and ‘Hopelessness/helplessness’ were the most common mental adjustment responses 4-6 months after surgery. They described cancer as a loss that they had accepted passively and believed that they were powerless to change fate. The ‘Cognitive fighting spirit’ response was the least common in this group.

**Mental adjustment to cancer and self-regulation:** A ‘Task perception and goal setting’ category was appropriate for 3 of 12 participants’ self-regulation responses. These participants described how they were ready to make any decision to fight the disease. One participant said:

*I'd hate to go through chemo again but it's just the fact of the matter that it just will have to happen so the disruption and the anxiety of going through that again is better than not doing anything and just letting the disease overtake your body so would be pretty, an easy decision to make to do all I can to fight the disease. (P12)*

Six participants’ self-regulation responses were categorized as ‘**Enacting**’. They explained that they were making all the changes related to their illness and said they had to be strong and positive. The following excerpts show this:

*I would be able to have a trip to Wanaka to catch up with my family down there... But that was a goal; well I can see now that it's probably not going to happen in the first half of this year. I've got to go back and see the surgeon again and it's just until I really recover from all these since last lot of illnesses and I get the feeling that I'm safe to go away from the hospital I might go a whole two or three weeks. (P15)*

*I need help as well. You know like if you came to me and said you need to do this I would, it's not that I'd be resistant to do it but I would need some guidance on how to do it, if you know what I mean. You know, if you suddenly came and said to me you've got to change your whole diet, I'd go well show me how, what do I need to do and those sorts of things. (P1)*

Three participants showed a ‘**Self-regulation difficulty**’ response. They reported that it was hard to get used to the new situation and that cancer seemed to be a kind of disability:

*Depends on what the change is. At this point in time I've had to slow down and my mobility...it's upsetting and it's annoying that I can't do what I used to do. (P14)*

*I feel handicapped really because I have to live with a bag rest of my life which I don't think is completely a helpful thing. (P8)*

Participants’ mental adjustment to cancer responses after surgery were compared with their self-regulation responses (Table 4.10).

**Table 4.10: Mental adjustment responses to colon cancer 4-6 months after surgery by self-regulation responses**

Self-regulation response	Task perception and goal setting (n=3)	Enacting self-regulation (n=6)	Self-regulation difficulty (n=3)
<b>Mental adjustment to cancer after surgery</b>	<b>Cognitive fighting spirit, (n=2)</b> P13,23	<b>Active fighting spirit, (n=3)</b> P1,5,15	<b>Hopelessness/helplessness, (n=2)</b> P8,14
	<b>Anxious preoccupation, (n=2)</b> P12,23	<b>Fatalism, (n=3)</b> P7,15,17,	<b>Fatalism, (n=2)</b> P8,14
		<b>Cognitive fighting spirit, (n=2)</b> P7,19	<b>Cognitive fighting spirit, (n=1)</b> P6
		<b>Anxious preoccupation, (n=2)</b> P1,19	

**Hopelessness/helplessness,**

(n=1)

P11

Participants who had accepted self-regulation to cancer as a task and set goals to fight the disease showed ‘Cognitive fighting spirit’ and ‘Anxious preoccupation’ as their mental adjustment to cancer responses. ‘Active fighting spirit’ and ‘Fatalism’ responses were shown by half of the participants enacting self-regulation to cancer. Conversely, ‘Hopelessness/helplessness’ and ‘Fatalism’ were the most common mental adjustment responses among participants who had difficulty in self-regulation to cancer.

**Mental adjustment to cancer and outcome expectations:** Seven of 12 participants expressed ‘**optimistic**’ expectations about the future. They believed that they would get good results at their future follow-ups and that the illness would not recur. Two participants stated:

*I think I should have a good future. I've got 12 grandchildren and four great grandchildren and as long as my daughter...if it's meant to be that she's going to be healed that will be just so much better. Because Mothers always want the best for the family so no I think I've got a good future ahead of me. Well that's what I'm aiming at. (P11)*

*I'm hoping for another good result and I think I've got over this first six months so the next six months will be another good result. Yes I'm positive about it all. (P5)*

Five out of twelve participants reported that they were living with ‘**Uncertainty**’ in respect of the future and they had to go under a monitoring programme for many years. They explained this as follows:

*It will just be a case of for the next – what it is – the next five years when I go into a monitoring type programme yeah I'll just tick off each year as it goes by and hope that nothing will reoccur. (P12)*

*I have no idea what is going to happen; hell I've just come back from chemotherapy...there's no sign of anything happening yet. (P1)*

A comparison was made of the mental adjustment to cancer responses 4-6 months after surgery of optimistic and uncertain participants (Table 4.11)

**Table 4.11: Mental adjustment responses to colon cancer 4-6 months after surgery by outcome expectations responses**

Outcome expectations	Optimistic (n=7)	Uncertain (n=5)
Mental adjustment to cancer after surgery	<b>Cognitive fighting spirit, (n=4)</b> P6,7,8,13	<b>Anxious preoccupation, (n=4)</b> P1,12,19,23
	<b>Fatalism, (n=3)</b> P5,8,15	<b>Fatalism, (n=2)</b> P1,14
	<b>Hopelessness/helplessness, (n=3)</b> P5,8,11	<b>Cognitive fighting spirit, (n=2)</b> P19,23
	<b>Active fighting spirit, (n=2)</b> P5,11	<b>Hopelessness/helplessness, (n=1)</b> P14
		<b>Active fighting spirit, (n=1)</b> P1

Optimistic participants mostly responded with ‘Cognitive fighting spirit’ and ‘Fatalism’ as their mental adjustment to cancer strategies 4-6 months after surgery while ‘Anxious preoccupation’ and ‘Fatalism’ were most common for participants uncertain about the future.

**Mental adjustment to cancer and social support:** Three categories were created for participants’ responses regarding the level of social support (high or low) and their family situation (married, living alone or with family): **high perceived social support, married and living with family (n=6), high perceived social support and living alone (n=3), low perceived social support, married and living with family (n=3).**

Participants who reported high perceived social support believed that they were receiving care, assistance and companionship from their social network. Family, friends, partners and religious groups were regarded as support sources. They described this as follows:

*Oh my family have been great. I've got a son, only one son here in Christchurch and one in Napier and they're both great. The one from Napier he came down when I had the surgery, the cancer surgery and he stayed here while I was in hospital. He came in twice a day to see me... (P5)*

*They're my friends and family they just do what I do and if they see me struggle sometimes and a wee bit concerned they ask if they can help and I let them or not whatever the case may be. Support's been there right from scratch. There's been no negative stuff at all. (P1)*

Participants who perceived low social support reported problems with their social networks which meant they did not get along with family or friends much. They reported family or friends upset them and they did not have any effect on the way they felt about cancer. They stated:

*Actually I think they all got a bigger shock than me when I listen now to different things and people tell me different thing it must have affected them quite badly. They must have thought "God she's had it, she's got cancer." (P6)*

*Well never rely on that you know, my children make fun of me yeah especially sometimes they hear noises of my stoma bag. Well I think they can't do much for me, this is your problem, and you have to cope with it. (P8)*

A comparison of mental adjustment to cancer responses 4-6 months post-surgery of three groups was made to find out how mental adjustment to colon cancer was correlated to social support. (Table 4.12).

**Table 4.12: Mental adjustment responses to colon cancer 4-6 months after surgery by social support status**

Social support status	Mental adjustment after surgery
High perceived social support, married and living with family, (n=6) P1,5,7,11,12,13	-Active fighting spirit, (n=3) P1,11,5
	-Cognitive fighting spirit, (n=2) P7,13
	-Anxious preoccupation, (n=2)

	P1,12
	- <b>Hopelessness/helplessness</b> , (n=2)
	P7,11
	- <b>Fatalism</b> , (n=2)
	P1,5
<b>High perceived social support, living alone, (n=3)</b>	- <b>Cognitive fighting spirit</b> , (n=2)
<b>P15,19,23</b>	P7,19
	- <b>Anxious preoccupation</b> , (n=2)
	P19,23
	- <b>Fatalism</b> , (n=1)
	P15
<b>Low perceived social support, married and living with family, (n=3)</b>	- <b>Hopelessness/helplessness</b> , (n=2)
<b>P6,8,14</b>	P8,14
	- <b>Fatalism</b> , (n=2)
	P8,14
	- <b>Cognitive fighting spirit</b> , (n=1)
	P6

Participants with high perceived social support who were married and living with family showed 'Active fighting spirit' as the most common mental adjustment to cancer response 4-6 months after surgery while those living alone mostly reported 'Cognitive fighting spirit' and 'Anxious preoccupation'. 'Hopelessness/helplessness', 'Fatalism' and 'Cognitive fighting spirit' were reported by most participants with low perceived social support.

### **Mental adjustment to cancer changes overtime**

The mental adjustment to cancer responses after receiving the diagnosis, after surgery and 4-6 months after surgery were compared to find out they changed over time (Table 4.13)

**Table 4.13: Mental adjustment responses to colon cancer changes over time**

After receiving diagnosis N=16	After surgery N=16	4-6 months after surgery N=12
-Anxious preoccupation (n=12)	-Active fighting spirit, (n=11)	-Cognitive fighting spirit, (n=6)
-Cognitive fighting spirit (n=9)	-Cognitive fighting spirit, (n=10)	-Fatalism, (n=5)
-Hopelessness/helplessness (n=8)	-Anxious preoccupation, (n=7)	-Anxious preoccupation, (n=4)
-Active fighting spirit (n=2)	-Hopelessness/helplessness, (n=6)	-Hopelessness/helplessness, (n=4)
-Fatalism (n=1)	-Fatalism, (n=5)	-Active fighting spirit, (n=3)

The findings show that mental adjustment to colon cancer changed over time. After receiving the diagnosis of cancer the ‘Anxious preoccupation’ and ‘Hopelessness/helplessness’ responses were common and there was a ‘Cognitive fighting spirit’ response among some of the participants. After surgery, when most patients were deciding about chemotherapy the ‘Active fighting spirit’ and ‘Cognitive fighting spirit’ were shown to be the most common responses, whereas the ‘Cognitive fighting spirit’ and ‘Fatalism’ were the most common 4-6 months after surgery.

Most of the participants responded with ‘Anxious preoccupation’ after receiving the diagnosis of cancer whereas a ‘Fighting spirit’ response was the most frequent adjustment strategy both after surgery and 4-6 months after surgery. ‘Active fighting spirit’ was used most after surgery and least after the diagnosis.

The ‘Anxious preoccupation’ response decreased after surgery and was shown by only few of the participants 4-6 months after surgery. Half of the participants reported a ‘Hopelessness/helplessness’ response immediately after receiving the diagnosis of cancer, but it decreased over time. Conversely; the ‘Fatalism’ response increased over time. While it was

the least frequently used adjustment strategy after diagnosis, it increased both immediately after surgery and 4-6 months after surgery.

## **Key findings**

Overall participants reported 'Physical distress' and 'Difficulties in sleeping' in hospital after surgery and 'Fitness and activity impairment' and 'Tiredness' a few weeks after surgery. 'Satisfaction with post-operative care' and 'Positive appraisal of surgery and well-being' were reported by most of the participants immediately after surgery and when interviewed respectively. Some negative emotional reactions such as 'Anxiety', 'Compulsive confrontation' and 'Hopelessness' were expressed by few participants. Fatigue was reported as the most common distress related to chemotherapy.

Overall participants demonstrated an 'Anxious preoccupation' mental adjustment strategy after receiving the diagnosis of cancer whereas a 'Fighting spirit' response was the most frequent one both after surgery and 4-6 months after surgery. The 'Anxious preoccupation' and 'hopelessness/helplessness' responses decreased over time, unlike the 'Fatalism' response which was increased over time.

Participants with high to moderate self-efficacy mostly expressed a 'Fighting spirit' at both after surgery and 4-6 months after surgery. In contrast, 'Hopelessness/helplessness', 'Anxious preoccupation' and 'Fatalism' were reported by participants with a low self-efficacy status.

In respect of the self-regulation responses, 'Fighting spirit' and 'Anxious preoccupation' were more common mental adjustment responses among participants who showed a task perception and goal setting self-regulation response whereas among participants who were enacting a self-regulation effort the most common responses were 'Fighting spirit' and 'Fatalism'. On the other hand, 'Hopelessness/helplessness', 'Anxious preoccupation', 'Fatalism' and 'Cognitive fighting spirit' were the most common mental adjustment responses among participants who had difficulty in self-regulation to cancer.

The 'optimistic expectations' response was linked to the 'Fighting spirit' and 'Fatalism' mental adjustment responses whereas 'Uncertainty about the future' was mostly linked to 'Anxious preoccupation', 'Hopelessness/helplessness' and 'Fatalism'.

Most of high perceived social support participants reported a 'Fighting spirit' adjustment response. In contrast, 'Anxious preoccupation', 'Hopelessness/helplessness' and 'Fatalism' were shown by low perceived social support participants.

# **Chapter Five**

## **Quantitative results**

### **Introduction**

This section presents the findings of twenty newly diagnosed colon cancer patients admitted to out-patient oncology clinics after surgery. All participants completed six questionnaires at two time points: immediately after surgery, and 4-6 months after surgery. The pack of questionnaires was made up of the following questionnaires: the Mini-Mental Adjustment to the Cancer Scale (Mini-MAC), the self-efficacy scale, the Revised Life Orientation Test (LOT-R), the Cognitive Emotion Regulation Questionnaire (CERQ), the Multidimensional Scale of Perceived Social Support (MSPSS), and the SF-12V2 Health Survey.

This chapter firstly describes the participants' demographics and then presents each instrument's findings in regards to the research questions. The key findings are presented in the conclusion.

### **Participants' demographics**

A total of 20 people newly diagnosed with colon cancer participated in the quantitative part of this study. All of the participants were New Zealand European, twelve (60%) were male and eight (40%) female. The majority (n=16, 80%) of participants were over 60 years old, 55% (n=11) were retired and 25% (n=5) were employed. At the time of study, most of the participants (n=11, 55%) were married, 45% (n=9) were living with their husband/wife or partner, and 35% (n=7) were living alone. The largest percentage (n=14, 70%) of participants were living in an urban area. Forty percent (n=8) of participants reported that their education level high school did not go to year 13, and eighty percent (n=16) of participants had an annual income of 10000-49000 NZ dollars. Thirty five percent (n=7) reported no religious affiliation and thirty percent (n=6) mentioned their religious affiliation as Protestant.

Eighty percent (n=16) of the participants received chemotherapy after surgery.

**Table 5.1: Sociodemographic and clinical characteristics of participants**

		<b>Number</b>	<b>Percent</b>
<b>Sex</b>	Male	12	60
	Female	8	40
<b>Age</b>	40-49	1	5
	50-59	3	15
	60-69	8	40
	>70	8	40
<b>Employment status</b>	Employed	5	25
	Self-employed	1	5
	Unable to work	3	15
	Retired	11	55
<b>Marital status</b>	Married	11	55
	Divorced	4	20
	Widowed	1	5
	Separated	2	10
	Never been married	1	5
	A member of unmarried couples	1	5
<b>Level of education</b>	High school but not to year 13	8	40
	High school completed year 13	4	20
	Some units at university	1	5
	Bachelor's degree	5	25
	Master's degree	1	5
<b>Annual income</b>	10000-29000	8	40
	30000-49000	8	40
	70000-99999	1	5
	100000 and more	1	5
<b>Home area</b>	Urban	14	70
	Rural	6	30
<b>Religious preference</b>	Protestant	6	30
	Catholic	2	10
	Jewish	1	5
	Others	2	10
	No religious affiliation	7	35
	Prefer not to say	1	5
	Missing	1	5
<b>House hold</b>	Husband/wife or partner	9	45
	Family	3	15
	Friends	1	5
	Alone	7	35
<b>Received chemotherapy</b>	Yes	16	80
	No	4	20

## The Mini-Mental Adjustment to Cancer Scale (Mini-MAC)

The Mental Adjustment to Cancer (MAC) scale is a 40-item self-report questionnaire to assess an individual's reactions to having cancer (Greer et al., 1989). Dimensions measured using the MAC Scale are: 'Fighting spirit', 'Helplessness/hopelessness', 'Anxious preoccupation', 'Fatalism', and 'Avoidance'. The MAC Scale assesses the extent to which patients adopt these responses in their adjustment to the diagnosis of cancer (Watson et al., 1988).

Mean scores and standard deviations of the Mini-MAC subscales at first and second follow-up are shown in Table 5.1.

**Table 5.2: Mean values, SD and range of scores on the Mini-MAC sub-scales immediately after surgery and 4-6 months after surgery**

	Immediately after surgery		4-6 months after surgery	
	Mean (SD)	Range	Mean (SD)	Range
<b>Anxious preoccupation total*</b>	16.85 (6.62)	8-31	14 (4.53)	8-24
<b>Anxious preoccupation mean**</b>	2.1 (0.83)	1-3.88	1.75 (0.57)	1-3
<b>Cognitive avoidance total*</b>	10 (3.31)	4-15	9.8 (3.6)	4-16
<b>Cognitive avoidance mean**</b>	2.5 (0.83)	1-3.75	2.45 (0.9)	1-4
<b>Fatalism total*</b>	14.25 (3.8)	5-20	15.2 (3.8)	8-20
<b>Fatalism mean**</b>	<b>2.85</b> (0.76)	1-4	<b>3.01</b> (0.75)	1.6-4
<b>Fighting spirit total*</b>	12.4 (2.72)	8-16	11.7 (3.11)	4-16
<b>Fighting spirit mean**</b>	<b>3.1 (0.68)</b>	2-4	<b>2.92</b> (0.88)	1-4
<b>Hopelessness/helplessness total*</b>	12 (5.6)	8-30	10.3 (3.2)	8-20
<b>Hopelessness/helplessness mean**</b>	1.5 (0.7)	1-3.75	1.3 (0.4)	1-2.5

\* Ranges: AP 8-32; CA 4-16; FA 5-20; FS 4-16; HH 8-32

\*\* Mean scores ranges: 1-4 (mean calculated by dividing total sum with number of items)

Following surgery, the most frequently used adjustment strategies were 'Fighting spirit' and 'Fatalism' (mean 3.1 and 2.85, respectively), whereas the least used strategies were 'Hopelessness/helplessness' and 'Anxious preoccupation' (mean 1.5 and 2.1, respectively).

At the second measurement point, 'Fatalism' and 'Fighting spirit' (mean 3.01 and 2.92, respectively) were shown to be the most frequently used adjustment strategies, and 'Hopelessness/helplessness' and 'Anxious preoccupation' (mean 1.3 and 1.75, respectively) were the least common mental adjustment responses. Except for 'Fatalism', all scores decreased at the second time point.

Paired t-tests were run to explore differences over time on the Mini-Mac sub-scales. Prior to conducting the analysis, the assumption of normal distribution was estimated and the assumption was considered statistically satisfied.

**Table 5.3: T-test results for Mini-MAC sub-scales immediately after surgery, and 4-6 months after surgery**

Mental adjustment to cancer	Immediately after surgery		4-6 months after surgery		95% CI for Mean Difference	t	df	Sig. (2-tailed)	Effect size
	M	SD	M	SD					
Anxious preoccupation	16.85	6.62	14	4.53	0.66, 5.04	2.73	19	<b>0.01*</b>	0.50
Cognitive avoidance	10	3.31	9.8	3.6	-1.09, 1.49	0.32	19	0.75	0.06
Fatalism	14.25	3.8	15.2	3.8	-2.48, 0.58	-1.3	19	0.21	0.25
Fighting spirit	12.4	2.72	11.7	3.11	-0.57, 1.97	1.15	19	0.26	0.24
Hopelessness/helplessness	12	5.6	10.3	3.2	-1.1, 4.5	1.27	19	0.22	0.37

\* Difference is significant at the 0.05 level (2-tailed).

‘Anxious preoccupation’ was the only Mini-Mac subscale which showed significant differences  $t(19) = 2.73, p = 0.01$ : it decreased by 16.91% 4-6 months after surgery compared with immediately after surgery. Although other sub-scales were not statistically different, ‘Hopelessness/helplessness’ with medium effect size showed 14.17% decrease after 4-6 month post-surgery (Table 5.3).

‘Cognitive avoidance’ and ‘Fighting spirit’ decreased 2% and 5.65%, respectively, while the effect size showed small differences.

## Self-Efficacy Scale

The self-efficacy scale assesses how an individual can perform difficult tasks or cope with new situations. It includes ten items and each item refers to successful coping and implies an internal-stable attribution of success (Schwarzer & Jerusalem, 1995).

This questionnaire includes 10 items with Likert scales ranging from 1 (not at all true) to 4 (exactly true). Summative score range from 10 to 40 points, and higher scores, show higher levels of SE. The questionnaire has been reported to have high reliability, stability, and construct validity (Melchior et al., 2013).

Table 5.4 displays means, standard deviations and t-test results for self-efficacy scores immediately after surgery and 4-6 months after surgery.

**Table 5.4: Descriptive statistics and t-test results for self-efficacy scores immediately after surgery, and 4-6 months after surgery**

	After surgery			4-6 months after surgery			95% CI for Mean Difference	t	df	Sig. (2-tailed)	Effect size
	M	SD	Range	M	SD	Range					
Self-efficacy	33.35	4.28	27-40	33.25	4.20	26-40	-1.73, 1.93	.115	19	.910	.012

The mean ( $\pm$ SD) Time One and Time Two scores of self-efficacy were 33.35 ( $\pm$ 4.28) and 33.25 ( $\pm$ 4.20), respectively. No differences of significance were noted between Time One and Time Two self-efficacy scores ( $t(19) = .115, p = 0.910$ ).

The relationship between self-efficacy with measures on the Mini-MAC sub-scales at two time points were investigated using “Pearson product-moment correlation coefficient” (Table 5.5).

**Table 5.5: Correlations between self-efficacy and Mini-Mac sub-scales immediately after surgery, and 4-6 months after surgery**

	Immediately after surgery		4-6 months after surgery	
	Pearson's r	P-value	Pearson's r	P-value
Anxious preoccupation	.323	.165	.235	.319
Cognitive avoidance	.156	.511	.132	.578
Fatalism	-.028	.913	-.508*	.022
Fighting spirit	.168	.479	.203	.391
Hopelessness/helplessness	.321	.168	-.198	.403

\* Correlation is significant at the 0.05 level (2-tailed).

The assumption of normality was tested and considered to be satisfied. There was a significant negative correlation between self-efficacy and ‘Fatalism’ 4-6 months after surgery,  $r = -.508, n = 20, p < 0.05$ , with high levels of self-efficacy associated with lower levels of ‘Fatalism’. The small sample size should indicate that the findings should be interpreted with caution.

## Revised Life Orientation Test (LOT-R)

The Revised Life Orientation Test (LOT-R) has been used by many studies on optimism and pessimism. Scheier and Carver (1985) developed LOT to measure optimism. The LOT has 8 item measures with 4 filler items to assess optimistic expectations; 4 items are worded in a positive direction, and 4 items worded in a negative direction. Responses are made on 5-point Likert scales ranging from 0 (strongly disagree) to 4 (strongly agree). After reversing negatively worded items, the overall optimism score was calculated by summation of all item

scores; a higher score indicates a greater optimism, ranging 0-32. Cronbach’s alpha has been reported as 0.82 (Scheier et al., 1994).

**Table 5.6: Descriptive statistics and t-test results for Optimism (LOT) scores after surgery and 4-6 months after surgery**

	After surgery			4-6 months after surgery			95% CI for Mean Difference	t	df	Sig. (2-tailed)	Effect size
	M	SD	Range	M	SD	Range					
Optimism (LOT)	19.85	2.96	15-26	18.7	2.66	14-24	-.35, 2.65	1.61	19	.124	.20

Table 5.6 presents the mean and standard deviation, and t-test results for optimism (LOT) after surgery, and 4-6 months after surgery. The mean ( $\pm$ SD) Time One and Time Two of optimism scores were 19.85 ( $\pm$ 2.96) and 18.7 ( $\pm$ 2.66) respectively. There were no significant differences between Time One and Time Two scores ( $t(19) = 1.61, p = 0.124$ ).

The relationship of optimism (LOT) with measures of Mini-MAC sub-scales at two time points was explored using Pearson product-moment correlation coefficient (Table 5.7). The assumption of normality was tested and considered to be satisfied.

**Table 5.7: Correlations between the optimism (LOT) scores and mental adjustment to cancer sub-scales immediately after surgery, and 4-6 months after surgery**

	Immediately after surgery		4-6 months after surgery	
	Pearson’s r	P-value	Pearson’s r	P-value
<b>Anxious preoccupation</b>	-.332	.153	-.302	.196
<b>Cognitive avoidance</b>	-.371	.108	-.255	.279
<b>Fatalism</b>	-.323	.165	<b>-.542*</b>	.014
<b>Fighting spirit</b>	.152	.524	.071	.765
<b>Hopelessness/helplessness</b>	-.385	.093	<b>-.546*</b>	.013

\* Correlation is significant at the 0.05 level (2-tailed).

There was a large, negative correlation between optimism and ‘Fatalism’ 4-6 months after surgery,  $r = -.542, n = 20, p < 0.05$ , with higher levels of optimism associated with lower levels of ‘Fatalism’. There was a strong, negative correlation between optimism and ‘Hopelessness/helplessness’ 4-6 months after surgery,  $r = -.546, n = 20, p < 0.05$ . Higher levels of optimism were correlated with low levels of ‘Hopelessness/helplessness’.

## Cognitive Emotion Regulation Questionnaire (CERQ-short)

The cognitive emotion regulation questionnaire (CERQ) was used to measure self-regulation. The CERQ is on a 5-point Likert scale ranging from 1((almost) never) to 5 ((almost) always). The subscale scores were obtained by summing each subscale item (ranging from 2 to 10). A higher score shows a more frequently used cognitive emotion regulation strategy (N. Garnefski & Kraaij, 2006b).

*Table 5.8: Descriptive statistics and t-test results for CERQ subscales scores immediately after surgery, and 4-6 months after surgery*

	Immediately after surgery			4-6 months after surgery			95% CI for Mean Difference	t	df	Sig. (2-tailed)	Effect size
	M	SD	Range	M	SD	Range					
Self-blame	3.95	2.26	2-10	4.40	2.54	2-10	-1.53, .64	-.86	19	.398	0.09
Other-blame	3.30	2.23	2-9	3.80	2.72	2-10	-1.58, .28	-1.47	19	.159	0.10
Rumination	4.95	1.96	2-8	5.30	2.59	2-10	-1.4, .71	-.67	19	.500	0.07
Catastrophizing	2.60	1.27	2-6	3.25	2.22	2-9	-1.35, .35	-1.23	19	.231	0.18
Putting into Perspective	6.20	2.19	2-10	6.80	2.60	2-10	-1.96, .77	-.92	19	.371	0.12
Positive Refocusing	5.65	2.45	2-10	7.15	2.52	2-10	-2.52, -.47	-3.06	19	<b>.006**</b>	.30
Positive Reappraisal	7.55	2.05	3-10	8.10	1.86	4-10	-1.47, .38	-1.23	19	.231	.14
Acceptance	7.65	1.93	4-10	8.65	1.87	4-10	-1.77, -.22	-2.70	19	<b>.014*</b>	.25
Refocus on Planning	6.30	2.56	3-10	7.00	2.22	3-10	-1.74, .34	-1.40	19	.176	.14

\* Difference is significant at the 0.05 level (2-tailed).

\*\* Difference is significant at the 0.01 level (2-tailed).

Table 5.8 presents the means and standard deviations, and t-test results for Cognitive Emotion Regulation Questionnaire (CERQ-short) subscales immediately after surgery, and 4-6 months after surgery. The mean ( $\pm$ SD) Time One and Time Two scores were: 3.95 ( $\pm$ 2.26) and 4.40 ( $\pm$ 2.54) for Self-blame; 3.30 ( $\pm$ 2.23) and 3.80 ( $\pm$ 2.72) for Other-blame; 4.95 ( $\pm$ 1.96) and 5.30 ( $\pm$ 2.59) for Rumination; 2.60 ( $\pm$ 1.27) and 3.25 ( $\pm$ 2.22) for Catastrophizing; 6.20 ( $\pm$ 2.19) and 6.80 ( $\pm$ 2.60) for Putting into Perspective; 5.65 ( $\pm$ 2.45) and 7.15 ( $\pm$ 2.52) for Positive Refocusing; 7.55 ( $\pm$ 2.05) and 8.10 ( $\pm$ 1.86) for Positive Reappraisal; 7.65 ( $\pm$ 1.93) and 8.65 ( $\pm$ 1.87) for Acceptance; and 6.30 ( $\pm$ 2.56) and 7.00 ( $\pm$ 2.22) for Refocus on Planning.

A significant 26.54% increase was found in relation to Positive Refocusing 4-6 months after surgery ( $t(19) = -3.06, p = 0.006$ ). At Time Two, Acceptance increased by 13.07% compared to immediately after surgery ( $t(19) = -2.70, p = 0.014$ ). Although other subscales were not statistically different, Positive Reappraisal, Refocus on Planning and Putting into Perspective increased 7.28%, 11.11% and 9.67% respectively with a small effect size. At 4-6 months after

surgery, the Self-blame, Other-blame, Catastrophizing and Rumination showed an increase of 11.4%, 15.15%, 25% and 7.07% respectively with a small effect size.

The relationships of CERQ subscales with measures of Mini-MAC sub-scales at two time points were investigated using “Pearson product-moment correlation coefficient” (Table 5.9). The assumption of normality was tested and considered to be satisfied.

**Table 5.9: Correlations between the CERQ subscales and mental adjustment to cancer subscales immediately after surgery, and 4-6 months after surgery**

Variables			Immediately after surgery	4-6 months after surgery	
Self-blame	Anxious preoccupation	r	.270	.224	
		Sig.	.249	.343	
	Cognitive avoidance	r	-.028	-.158	
		Sig.	.906	.506	
	Fatalism	r	-.170	-.156	
		Sig.	.474	.511	
	Fighting spirit	r	.260	.315	
		Sig.	.268	.176	
	Hopelessness/helplessness	r	.363	-.229	
		Sig.	.116	.331	
	Other-blame	Anxious preoccupation	r	<b>.729**</b>	.324
			Sig.	.000	.163
Cognitive avoidance		r	.212	.231	
		Sig.	.369	.327	
Fatalism		r	.239	.150	
		Sig.	.311	.528	
Fighting spirit		r	.018	.034	
		Sig.	.939	.886	
Hopelessness/helplessness		r	<b>.659**</b>	.011	
		Sig.	.002	.963	
Rumination	Anxious preoccupation	r	<b>.474*</b>	<b>.523*</b>	
		Sig.	.035	.018	
	Cognitive avoidance	r	<b>.528*</b>	.148	
		Sig.	.017	.534	

	Fatalism	r	.340	.213	
		Sig.	.142	.368	
	Fighting spirit	r	.191	.116	
		Sig.	.419	.627	
	Hopelessness/helplessness	r	.322	.344	
		Sig.	.166	.138	
Catastrophizing	Anxious preoccupation	r	<b>.735**</b>	<b>.750**</b>	
		Sig.	.000	.000	
	Cognitive avoidance	r	<b>.486*</b>	.372	
		Sig.	.030	.106	
	Fatalism	r	.034	-.037	
		Sig.	.886	.878	
	Fighting spirit	r	.066	.340	
		Sig.	.782	.143	
	Hopelessness/helplessness	r	<b>.665**</b>	.110	
		Sig.	.001	.645	
	Putting into perspective	Anxious preoccupation	r	-.009	.294
			Sig.	.971	.208
Cognitive avoidance		r	.349	.400	
		Sig.	.132	.081	
Fatalism		r	-.032	.026	
		Sig.	.895	.915	
Fighting spirit		r	.304	.161	
		Sig.	.193	.498	
Hopelessness/helplessness		r	.004	-.131	
		Sig.	.986	.581	
Positive refocusing		Anxious preoccupation	r	.298	.360
			Sig.	.202	.119
	Cognitive avoidance	r	<b>.803**</b>	<b>.614**</b>	
		Sig.	.010	.004	
	Fatalism	r	-.108	-.036	
		Sig.	.649	.879	
	Fighting spirit	r	<b>.479*</b>	.207	
		Sig.	.033	.380	

	Hopelessness/helplessness	r	.223	.092	
		Sig.	.345	.699	
Positive reappraisal	Anxious preoccupation	r	-.175	-.169	
		Sig.	.461	.477	
	Cognitive avoidance	r	.193	.168	
		Sig.	.416	.478	
	Fatalism	r	.095	-.279	
		Sig.	.689	.234	
	Fighting spirit	r	.296	.214	
		Sig.	.205	.364	
	Hopelessness/helplessness	r	-.073	<b>-.474*</b>	
		Sig.	.759	.035	
	Acceptance	Anxious preoccupation	r	-.083	-.118
			Sig.	.729	.620
Cognitive avoidance		r	.107	.130	
		Sig.	.652	.585	
Fatalism		r	.034	-.279	
		Sig.	.887	.234	
Fighting spirit		r	-.032	.017	
		Sig.	.893	.943	
Hopelessness/helplessness		r	.113	-.061	
		Sig.	.637	.799	
Refocus on planning		Anxious preoccupation	r	.053	.282
			Sig.	.826	.228
	Cognitive avoidance	r	-.124	.184	
		Sig.	.601	.436	
	Fatalism	r	.057	.168	
		Sig.	.812	.478	
	Fighting spirit	r	.088	.175	
		Sig.	.713	.461	
	Hopelessness/helplessness	r	.004	-.067	
		Sig.	.988	.780	

\*\* Correlation is significant at the 0.01 level (2-tailed).

\* Correlation is significant at the 0.05 level (2-tailed).

A large positive correlation was found between Other-blame with ‘Anxious preoccupation’ ( $r=.73, p<0.001$ ), and ‘Hopelessness/helplessness’ ( $r=.66, p=.002$ ), which indicated that high levels of Other-blame was correlated with high levels of ‘Anxious preoccupation’ and with ‘Hopelessness/helplessness’ immediately after surgery.

Correlations between Rumination and ‘Anxious preoccupation’ immediately after surgery were moderate, positive and statistically significant ( $r=.47, p=.035$ ), while this relationship was strong and positive 4-6 months after surgery ( $r=.52, p=0.018$ ). A significant strong positive relation was found for Rumination and ‘Cognitive avoidance’ immediately after surgery ( $r=.53, p=.017$ ).

Catastrophizing was significantly correlated with ‘Anxious preoccupation’, immediately and 4-6 months after surgery ( $r=.74, p<0.001$  and  $r=.75, p<0.001$ , respectively). Therefore, Catastrophizing was strongly correlated with ‘Hopelessness/helplessness’ ( $r=.67, p=0.001$ ) immediately after surgery. A medium positive correlation was shown between catastrophizing and ‘Cognitive avoidance’ immediately after surgery ( $r=.49, p=.030$ ).

Positive refocusing and ‘Cognitive avoidance’ were shown to have a significant, strong and positive correlation immediately after surgery ( $r=.8, p=.010$ ) and 4-6 months after surgery ( $r=.61, p=.004$ ).

A significant medium and negative correlation between a Positive reappraisal and ‘Hopelessness/helplessness’ was captured by Pearson product correlation 4-6 months after surgery ( $r=-.47, p=.035$ ).

### **Multidimensional Scale of Perceived Social Support (MSPSS)**

Multidimensional Scale of Perceived Social Support (MSPSS) is a 12-item self-report measure on a 7-point Likert-type scale ranging from very strongly disagree (1) to very strongly agree (7); it seeks the perceived social support from three sources: family, friends and a significant other.

**Table 5.10: Descriptive statistics and t-test results for Perceived Social Support (MSPSS) scores immediately after surgery, and 4-6 months after surgery**

	Immediately after surgery			4-6 months after surgery			95% CI for Mean Difference	t	df	Sig. (2-tailed)	Effect size
	M	SD	Range	M	SD	Range					
<b>MSPSS</b>	69.55	15.23	19-84	69.75	15.61	19-84	-3.63, 3.23	-1.22	19	.904	.006

Table 5.10 presents the mean and standard deviation, and t-test results for perceived social support (MSPSS) after surgery, and 4-6 months after surgery. The mean ( $\pm$ SD) Time One and Time Two of perceived social support scores were 69.55 ( $\pm$ 15.23) and 69.75 ( $\pm$ 15.61) respectively. There were no significant differences between scores at Time One and Time Two ( $t(19) = -1.22, p = 0.904$ ).

The relationship of perceived social support (MSPSS) with Mini-MAC sub-scale scores immediately, and 4-6 months after surgery, were investigated using “Pearson product-moment correlation coefficient” (table 5.11). The assumption of normality was tested and considered to be satisfied.

**Table 5.11: Correlations between the perceived social support and mental adjustment to cancer subscales after surgery, and 4-6 months after surgery**

	After surgery		4-6 months after surgery	
	r	Sig.	r	Sig.
<b>Anxious preoccupation</b>	.252	.284	.350	.131
<b>Cognitive avoidance</b>	.172	.469	.251	.285
<b>Fatalism</b>	.047	.845	-.123	.605
<b>Fighting spirit</b>	-.083	.727	-.038	.873
<b>Hopelessness/helplessness</b>	.146	.539	.044	.852

There was no significant correlation between perceived social support and subscales of mental adjustment to cancer immediately, and 4-6 months after surgery.

## SF-12V2 Health Survey

SF-12v2 items are scored so that a higher score indicates a better health state. A raw score is computed for each domain and then each raw scale was transformed to a score on 0-100 scale. This transformation converts the lowest and highest possible scores to zero and 100; scores between these values show the percentage of the possible score achieved.

$$\text{Transformed scale} = \frac{(\text{Actual raw score} - \text{lowest possible raw score})}{\text{Possible raw score range}} \times 100$$

Table 5.12 presents the mean and standard deviation, and t-test results for SF-12V2 Health Survey domain scores immediately after surgery, and 4-6 months after surgery.

**Table 5.12: Descriptive statistics and t-test results for SF-12v2 domains scores immediately after surgery and 4-6 months after surgery**

	Immediately after surgery		4-6 months after surgery		95% CI for Mean Difference	t	df	Sig. (2-tailed)	Effect size
	M	SD	M	SD					
General health	70.4	24.11	66.4	22.38	-7.16, 15.16	.750	19	.462	.085
Physical functioning	48.75	30.86	42.5	30.46	-11.50, 24.00	.737	19	.470	.10
Role physical	54.75	24.83	56.70	23.96	-13.38, 9.49	-.357	19	.725	.039
Role emotional	75.55	25.55	69.25	27.11	-5.05, 17.65	1.161	19	.260	.118
Bodily pain	68.75	32.32	77.50	25.52	-24.97, 7.47	-1.129	19	.273	.148
Vitality	47.50	25.52	46.25	16.77	-11.03, 13.53	.213	19	.834	.028
Mental health	76.60	17.82	79.75	16.95	-11.82, 4.88	-.821	19	.422	.090
Social functioning	67.50	30.45	75.00	24.33	-18.30, 3.30	-1.453	19	.163	.134

The mean ( $\pm$ SD) Time One and Time Two scores were: 70.4 ( $\pm$ 24.11) and 66.4 ( $\pm$ 22.38) for General health; 48.75 ( $\pm$ 30.86) and 42.5 ( $\pm$ 30.46) for Physical functioning; 54.75 ( $\pm$ 24.83) and 56.70 ( $\pm$ 23.96) for Role physical; 75.55 ( $\pm$ 25.55) and 69.25 ( $\pm$ 27.11) for Role emotional; 68.75 ( $\pm$ 32.32) and 77.50 ( $\pm$ 25.52) for Bodily pain; 47.50 ( $\pm$ 25.52) and 46.25 ( $\pm$ 16.77) for Vitality; 76.60 ( $\pm$ 17.82) and 79.75 ( $\pm$ 16.95) for Mental health; and 67.50 ( $\pm$ 30.45) and 75.00 ( $\pm$ 24.33) for Social functioning. There were no significant differences between Time One and Time Two scores.

The relationships of SF-12v2 domains with measures of Mini-MAC sub-scales at two time points were investigated using “Pearson product-moment correlation coefficient”. The assumption of normality was tested and considered to be satisfied. Table 5.13 shows the results.

**Table 5.13: Correlations between the SF-12v2 domains and mental adjustment to cancer subscales immediately after surgery, and 4-6 months after surgery**

Variables			Immediately After surgery	4-6 months after surgery
General health	Anxious preoccupation	r	.124	.074
		Sig.	.604	.757
	Cognitive avoidance	r	.120	.290
		Sig.	.615	.215
	Fatalism	r	-.401	-.146
		Sig.	.080	.538
	Fighting spirit	r	.375	-.139
		Sig.	.103	.558
Hopelessness/helplessness	r	.042	<b>-.537*</b>	

		Sig.	.860	.015	
Physical functioning	Anxious preoccupation	r	-.239	-.076	
		Sig.	.310	.749	
	Cognitive avoidance	r	-.077	.082	
		Sig.	.746	.732	
	Fatalism	r	-.434	-.442	
		Sig.	.056	.051	
	Fighting spirit	r	.085	.142	
		Sig.	.723	.552	
	Hopelessness/helplessness	r	-.298	-.151	
		Sig.	.202	.524	
	Physical role	Anxious preoccupation	r	-.280	-.006
			Sig.	.232	.980
Cognitive avoidance		r	-.048	.125	
		Sig.	.840	.601	
Fatalism		r	.216	.286	
		Sig.	.361	.222	
Fighting spirit		r	.290	.074	
		Sig.	.214	.758	
Hopelessness/helplessness		r	<b>-.485*</b>	-.080	
		Sig.	.030	.736	
Role emotional	Anxious preoccupation	r	-.421	-.225	
		Sig.	.065	.339	
	Cognitive avoidance	r	-.343	-.283	
		Sig.	.138	.227	
	Fatalism	r	-.408	-.258	
		Sig.	.074	.272	
	Fighting spirit	r	.034	-.216	
		Sig.	.886	.359	
	Hopelessness/helplessness	r	<b>-.550*</b>	.005	
		Sig.	.012	.982	
Bodily pain	Anxious preoccupation	r	-.035	.250	
		Sig.	.882	.287	
	Cognitive avoidance	r	-.246	.049	

	Fatalism	Sig.	.188	.838	
		r	-.254	-.114	
	Fighting spirit	Sig.	.280	.632	
		r	.209	-.156	
	Hopelessness/helplessness	Sig.	.376	.312	
		r	-.321	-.219	
		Sig.	.168	.353	
Vitality	Anxious preoccupation	r	-.244	-.052	
		Sig.	.300	.828	
	Cognitive avoidance	r	-.249	.009	
		Sig.	.289	.971	
	Fatalism	r	.115	-.319	
		Sig.	.629	.171	
	Fighting spirit	r	.053	.129	
		Sig.	.824	.589	
	Hopelessness/helplessness	r	<b>-.499*</b>	.022	
		Sig.	.025	.426	
	Mental health	Anxious preoccupation	r	<b>-.690**</b>	.171
			Sig.	.001	.470
Cognitive avoidance		r	-.220	.180	
		Sig.	.351	.447	
Fatalism		r	.050	.078	
		Sig.	.834	.743	
Fighting spirit		r	.015	.258	
		Sig.	.949	.272	
Hopelessness/helplessness		r	<b>-.515*</b>	.023	
		Sig.	.020	.923	

\*\* Correlation is significant at the 0.01 level (2-tailed).

\* Correlation is significant at the 0.05 level (2-tailed).

A medium and negative correlation was shown between General health and 'Hopelessness/helplessness' immediately after surgery ( $r=-.537$ ,  $p=.015$ ), which indicated that high levels of General health was correlated with low levels of 'Hopelessness/helplessness'. This negative correlation was captured between physical role ( $r=-.485$ ,  $p=.030$ ), emotional role

( $r=-.550$ ,  $p=.012$ ), vitality ( $r=-.499$ ,  $p=.025$ ) and mental health ( $r=-.515$ ,  $p=.020$ ) with 'Hopelessness/helplessness' immediately after surgery; this indicates that high levels of these domains were correlated to low levels of 'Hopelessness/helplessness'. Mental health was shown to have a significant strong and negative correlation with 'Anxious preoccupation' immediately after surgery ( $r=-.690$ ,  $p=.001$ ).

## **Key findings**

Generally, participants reported "Fighting spirit" and "Fatalism" as the most frequently used mental adjustment strategies immediately, and 4-6 months after surgery. The level of "Anxious preoccupation" dramatically decreased at Time Two as well as a clinical decrease for "Hopelessness/helplessness", "Cognitive avoidance" and "Fighting spirit".

Correlation studies suggest that high levels of self-efficacy associated with lower levels of "Fatalism". In the same way, high levels of optimism were correlated with low levels of "Fatalism" and "Hopelessness/helplessness".

The participants reported higher levels of positive refocusing and acceptance at Time Two. High levels of Other-blame were correlated with high levels of "Anxious preoccupation" and "Hopelessness/helplessness" immediately after surgery. Participants who were using Rumination showed higher levels of "Anxious preoccupation" and "Cognitive avoidance". In like manner, participants taking high levels of Catastrophizing showed more frequent using of "Anxious preoccupation", "Hopelessness/helplessness" and "Cognitive avoidance". Participants with positive refocusing strategy reported more "Cognitive avoidance". Conversely, positive reappraisal was correlated to less "Hopelessness/helplessness".

Participants with better levels of General health, Physical role, Emotional role, Vitality and Mental health showed low levels of "Hopelessness/helplessness". A better mental health condition was correlated to lower levels of "Anxious preoccupation".

## **Chapter six**

### **Discussion and conclusion**

#### **Introduction**

In view of the fact that the invasive nature of colon cancer and its treatments lead to some level of distress, negative psychosocial outcomes and poor quality of life are inevitable. In the present study, the participants described experiencing several stages during their journey: adjusting to receiving their diagnosis of cancer; deciding about and recovering from colon resection surgery and perhaps having a stoma; getting ready to start adjuvant chemotherapy; struggling with chemotherapy side effects; and waiting to hear word of being disease-free or having a recurrence. Difficulties in adjustment to any of these stages may lead to emotional distress which impacts on compliance with treatments, quality of life and mortality. The period of the first few months following a diagnosis of cancer is challenging, and adjustment is an ongoing process. Many theories have described that both cognitive and social factors impact on adjustment to cancer, and that cancer patients' adjustment can be predicted by these factors. Bandura's socio-cognitive theory is one of these theories which can be used to assess adjustment to cancer through behavioural, personal and environmental factors. Therefore, this study aimed to explore changes in mental adjustment to the diagnosis of colon cancer over time and how they are correlated with socio-cognitive theory constructs. The study used a mixed methods design with an embedded qualitative strand to explore mental adjustment changes and its correlations with self-efficacy, outcome expectations and self-regulation as personal and behavioural factors, and social support as the environmental factor of SCT over a 6 month period.

This chapter begins with a summary of key findings, and then the meaning and importance of the findings are explained and interpreted within the context of similar studies. The mental adjustment to cancer changes will be presented in 5 stages: immediately after receiving a diagnosis of cancer; awaiting surgery; immediately after surgery in hospital; a few weeks after surgery before starting adjuvant chemotherapy; and 4-6 months after surgery. Afterwards, the mental adjustment to cancer will be discussed in correlation with SCT constructs including self-efficacy, outcome expectations, self-regulation and social support. In addition, the clinical relevance of the findings is presented. The study's limitations are acknowledged, followed by suggestions for further research and an overall conclusion.

The overall findings from this study show that an ‘anxious preoccupation’ was the most common mental adjustment category immediately after receiving a diagnosis of cancer, whereas a ‘fighting spirit’ and ‘fatalism’ were the most frequently used ones immediately and 4-6 months after surgery. The level of ‘anxious preoccupation’, ‘hopelessness/helplessness’, ‘cognitive avoidance’ and ‘fighting spirit’ decreased over time, unlike the ‘fatalism’ which increased over time.

In this study, the participants who demonstrated high levels of self-efficacy were more likely to use a ‘fighting spirit’ mental adjustment. On the other hand, ‘hopelessness/helplessness’, ‘anxious preoccupation’ and ‘fatalism’ were expressed by participants with low self-efficacy status.

Furthermore, participants whose outcome expectation was marked by an optimistic view towards the future continued to have a ‘fighting spirit’ mental adjustment, but an uncertainty towards the future was associated mostly with ‘anxious preoccupation’, ‘hopelessness/helplessness’ and ‘fatalism’.

Moreover, the participants who were trying to do a self-regulating effort to adjust to colon cancer showed more positive refocusing and acceptance over time, while ones who perceived adjusting to colon cancer disease as a task and set goals to manage this new situation reported a ‘fighting spirit’ and ‘anxious preoccupation’ more frequently. Participants who were enacting self-regulation efforts expressed ‘fighting spirit’ and ‘fatalism’. In contrast, ‘hopelessness/helplessness’ and ‘anxious preoccupation’ were more common among patients who had difficulty in self-regulation for colon cancer. Furthermore, the participants who reported other-blaming, rumination and catastrophizing as their self-regulation responses showed more frequent use of ‘anxious preoccupation’, ‘hopelessness/helplessness’ and ‘cognitive avoidance’.

Additionally, most participants with high perceived social support reported a ‘fighting spirit’ mental adjustment. In contrast, ‘anxious preoccupation’, ‘hopelessness/helplessness’ and ‘fatalism’ were shown by participants with low perceived social support.

**Mental adjustment after receiving a diagnosis of colon cancer:** In the present study, participants tried to recall their feelings at diagnosis time during Interview One which was a few weeks after surgery. Participants responded mostly by ‘anxious preoccupation’, ‘cognitive fighting spirit’ and ‘hopelessness/helplessness’.

Many studies have employed a longitudinal design to track coping and adjustment changes over time, but only a few have explored the period immediately after diagnosis of cancer. Admittedly, cancer is a traumatic experience and a variety of cognitive responses are anticipated. Much of the literature appeared to confirm a high level of distress and psychiatric symptoms after cancer diagnosis (Absalom et al., 2011; Fang, Fall, Mittleman, Sparen, et al., 2012; Hulbert-Williams et al., 2012; Linden et al., 2012; Nekolaichuk et al., 2011). The 'anxious preoccupation' was expressed by 'difficulty believing' and were described by feeling shock, disbelief and hard to believe that this had happened to them. Participants described their anxiety as an overwhelming feeling and having a stressful time to take an active role in their treatment decisions. The unpredictable nature of cancer made patients uncertain about the prognosis and future, which was described as fear by some participants. Trying to contact others to seek support and information was shown by participants as indicators of anxiety. Similar to our findings, it has been documented that women with breast cancer express the highest levels and percentages of distress at diagnosis time when the extent and aggressiveness of the disease is still unknown (Andreu et al., 2012). Likewise, the negative mental adjustment responses including 'anxious preoccupation' and 'hopelessness/helplessness' have been shown to be associated with distress for thyroid cancer patients (Seok et al., 2013). Distress includes a variety of negative psychological outcomes and poor quality of life, and it has been considered as the sixth vital sign in cancer care (Gao et al., 2010; Gil et al., 2012; Hulbert-Williams et al., 2012; Linden et al., 2012). At diagnosis, the participants knew their tumour was malignant, but they were uncertain what the future held for them. These findings receive support from literature which shows that diagnosis of cancer accompanied by sense of threat, uncertainty and anxiety could be a result of the fear of suffering and death (Gil et al., 2012). These findings show that the health system needs to pay particular attention to patients' distress at diagnosis time, since the emotional distress (anxiety and depression) reduces quality of life and impacts compliance with medical treatment negatively; it might also result in an elevated risk of mortality (Linden et al., 2012).

A 'hopelessness/helplessness' towards the diagnosis of colon cancer was shown as a loss. Participants expressed their sadness and disappointment as a sense of loss because of unwanted changes in their body and an uncertain future. These ideas were similar to other literature which appraised prostate cancer as harm/loss accompanied by negative emotions such as depressive symptoms and anxiety (Bjorck et al., 1999).

Greer, Moorey, and Watson (1989) defined 'fighting spirit' as accepting the diagnosis, using the word 'cancer', being determined to fight the illness, trying to obtain as much information as possible and adopting an optimistic attitude. At this study, the 'fighting spirit' category was divided into 'cognitive fighting spirit' and 'active fighting spirit'. Bjorck et al. (1999) indicated that only people with higher self-esteem are able to take a 'fighting spirit' towards cancer. In a grounded theory approach to understand the cancer-coping process, Knott, Turnbull, Olver, and Winefield (2012) illustrated that the patients who view changes as a challenge and not a threat, have high levels of personal control over their lives. But, such a coping style would result in increased patient burden. However, the 'fighting spirit' has been documented as a predictor of better quality of life (Ferrero et al., 1994; Kershaw et al., 2004; Yeung & Lu, 2014b). After receiving the diagnosis of malignancy, participants showed a 'cognitive fighting spirit' which demonstrated that they were fighting mentally by accepting and confronting the diagnosis, and having a positive attitude towards disease even although viewing it as a challenge.

**Mental adjustment awaiting surgery:** At time point one, some of the participants talked about their pre-surgery experience and few of them reported some levels of anxiety. This result is confirmed by the study of Whynes and Neilson (1997) on general health status, symptoms and emotional reactions before surgery for colorectal cancer. They showed that more than 80% of patients reported the presence of anxiety, worry and nervousness before the surgery. In general, it is normal to feel anxious before surgery, but when it is overwhelming, it might have postoperative consequences. Mayo et al. (2011), in their study of impacts of a pre-rehabilitation program for colorectal surgery, found that a high level of anxiety is a significant predictor of poorer postoperative recovery. Anxiety has been shown to affect pain, mood and physical recovery postoperatively (Munafò & Stevenson, 2001). In a cross-sectional study, newly diagnosed thyroid cancer patients waiting for surgery reported 'anxious preoccupation' and 'helplessness/hopelessness' as the most significant factors predicting distress (Seok et al., 2013). On the other hand, anxiety may have a protective role and help to escape from the danger which is called 'fight or flight response'. Mayo et al. (2011) also found that patients who were anxious because of anticipation and fear of the colorectal surgery took part in the exercise program more actively. In this study, patients described a 'compulsive confrontation' to surgery. They explained that they had to accept and get the surgery done. This response may be a reaction to prevent anxiety and escape a stressful situation. Some other participants reported the 'surgery information need' because of the unknown extent and aggressiveness of

the disease. In the same way, a qualitative interpretive study on patients' experiences of a preoperative information session with a nurse found that patients feel confirmed in an information session and healthcare professionals should concern more information call during hospitalization (Aasa, Hovback, & Bertero, 2013).

**Mental adjustment immediately after surgery at hospital:** In this study, participants reported physical distress and difficulty in sleeping mostly related to catheters, tubes, staples, bandaging and stoma bag after operation at hospital. However, they were satisfied with post-operative care of New Zealand health care services. They expressed trust in hospital staff and felt they were trying their best. These findings can be used to interpret later mental adjustment responses, since satisfied patients are usually more adherent to physician recommendations and report better physical and mental health status (Fenton, Jerant, Bertakis, & Franks, 2012; Zolnierek & DiMatteo, 2009).

**Mental adjustment post-surgical period before starting adjuvant chemotherapy:** Three to six weeks after surgery, the participants reported that they were experiencing 'fitness and activity impairment', 'tiredness', 'alteration in bowel elimination pattern' and 'abdominal pain'. This result corroborates previous studies. Low levels of symptom distress (pain, fatigue, constipation, diarrhoea and loss of appetite) are congruent with clinical expectations after surgery for cancer of colon; the impaired physical performance and loss of energy are common in patients receiving cancer treatments. The fatigue is a frequently reported problem after surgery for cancer which can affect psychosocial situation, mood disorders and physical activity (Dimeo et al., 2004; Galloway & Graydon, 1996). The assessment of symptom distress has been conducted by Pan et al. (2011) through a longitudinal study among 35 colorectal cancer patients 1 week and 1, 2 and 3 months after colorectal cancer surgery; in this study, the distress level of diarrhoea was recognized as the highest at 1 week after surgery, but it gradually decreased thereafter.

Surgery on the bowel is a major physiological stress, and fitness and activity impairment is expected. The treatment side effects such as fatigue and physical limitation may affect expectations of life, and patients may miss their normal life and feel worried about cancer recurrence (Hoffman et al., 2013). However, our findings showed that participants appraised their surgery result and recovery progress positively. Appraisal and reappraisal occur throughout the cancer journey (Hoffman et al., 2013). Cancer survivors who employ high threat appraisal and low coping appraisal experience more fear of recurrence of cancer (McGinty et

al., 2012). The literature has pointed out stress appraisal as the strongest and the most consistent predictor of adjustment (Groarke et al., 2013). In this study, the findings indicated that in spite of suffering symptom distress and functional decline, participants expressed a positive appraisal of surgery and well-being. This optimistic view can help to interpret mental adjustment at this stage. Although participants were suffering symptom distress after surgery, and were receiving information about adjuvant chemotherapy and its possible side effects, they showed mostly 'active fighting spirit' and 'cognitive fighting spirit'. They were determined to fight cancer and they were trying to have a positive attitude by using spirituality. Keeping themselves busy with treatments, follow ups and activities were mentioned as fighting-spirit mental adjustment category. Participants mentioned feeling blessed that they were not in a worse situation, and the use of humour was reported as a way to cope with the new situation. The cancer and its treatments were called as a challenge for participants which is an inevitable part of life. These strategies can be categorized as problem-focused and emotion-focused coping strategies. The problem-focused coping strategies, which are accompanied by more control over the disease, have been documented as a significant predictor for lower anxiety/depression symptoms (Osowiecki & Compas, 1999). Active coping has been reported as a predictor for higher quality of life in advanced breast cancer patients in Thailand (Kershaw et al., 2004). In Sweden, a longitudinal study reported 'fighting spirit' as the most commonly used adjustment response at 1 and 12 months after start of treatment for laryngeal cancer (Johansson et al., 2011). Our findings showed that the "Satisfaction with post-operative care" and "positive appraisal of surgery and well-being" were described by most participants immediately after surgery. This response is a kind of emotion-focused coping strategy which has been documented to help adjustment and health status (Annette. L. Stanton et al., 2000). This can be an explanation as to why participants used more 'fighting spirit' mental adjustment. The confidants (physicians) and satisfaction with confidants have been reported as predictive for 'fighting spirit' (Akechi, Kugaya, et al., 1998), and patient performance status has been documented as the other predictor of 'fighting spirit' (Akechi, Okamura, et al., 1998; Okano et al., 2001). However in this study, in spite of reporting a 'fitness and activity impairment' by most participants, 'fighting spirit' was the common adjustment response. People react to diagnosis of cancer and treatments by a cognitive process of appraising and reappraising the nature of the stressor (Hoffman et al., 2013). Since the participants' appraisal of recovery were positive and they reported a satisfaction and confidence in health professionals, the active mental adjustment strategies such as fighting spirit are more expected.

While most of the participants were showing a ‘fighting-spirit’, a few participants expressed an ‘anxious preoccupation’ mental adjustment. They explained that they were living with an uncertainty related to unknown aspects of the disease, and they were seeking information about an uncertain future. They described their life as insecure and unpredictable because they didn’t know what the future held. Cancer was preventing plans because it had changed the way of life and it was the main goal for them to deal with. These findings are supported by the literature which indicate that patients experience some uncertainty and need discharge health information after a colon resection for cancer, and patients with a higher level of uncertainty need more discharge information (Galloway & Graydon, 1996). The cancer survivor should define new life goals and life roles that are more achievable. This situation is completely different to pre-cancer goals, particularly for younger cancer patients (Hoffman et al., 2013). ‘Anxious preoccupation’ was the most common response immediately after surgery and it is expected to be shown over time. This finding is in line with Hulbert-Williams et al. (2012) who have pointed out that earlier levels of anxiety are accounted as one of the most important predictors of mental adjustment over time. Another likely explanation for showing an ‘anxious preoccupation’ was the time of adjuvant chemotherapy planning which triggers significant distress. This possibility can be linked to the reported ‘uncertainty’ by participants. The literature confirms that cancer patients experience clinical anxiety and depression at some point during the course of their disease (Hulbert-Williams et al., 2012; Nekolaichuk et al., 2011).

**Mental adjustment 4-6 months after surgery:** For participants who had undergone an adjuvant chemotherapy, fatigue was reported as the most common problem during and after chemotherapy. This finding is consistent with a previous study which reported fatigue as the most common side effect among colorectal cancer patients receiving chemotherapy (Dikken & Sitzia, 1998). Aslam et al. (2014) studied the side effects of chemotherapy in cancer patients, and reported fatigue as the second most common one after weakness.

After completion of adjuvant chemotherapy, ‘cognitive fighting spirit’ and ‘fatalism’ were the most common mental adjustment reported categories. Participants expressed ‘fighting spirit’ through a ‘compulsory confrontation’ by explaining that they had to deal with cancer and were trying to adjust to it. However, they appraised that they were coping well and they had recovered from disease after receiving chemotherapy. It has been confirmed that higher levels of positive attitude and positive reappraisal are correlated with lower levels of emotional distress (Schnoll, Mackinnon, Stolbach, & Lorman, 1995).

A 'fatalism' was expressed by a passive acceptance. Participants explained that they had accepted cancer but not as an important part of their life and nothing could change it and there was nothing they could do about it. It was believed that this new situation would go ahead and it was impossible to have any control over it. An uncertainty of recurrence or a second cancer was suggested by the study findings. Some previous studies suggested that 'passive acceptance' and 'fatalism' are correlated with poor psychological adjustment and well-being (Ferrero et al., 1994; Hack & Degner, 2004; Schnoll et al., 1998). Similarly, a study on 238 cancer survivors showed that higher 'fighting spirit' was related to higher quality of life, whereas higher 'fatalism' was related to lower quality of life (Yeung & Lu, 2014b). On the other hand, Harandy et al. (2009), examining coping styles among Iranian breast cancer survivors, found that a fatalistic view is a facilitator for medical follow-up and treatment engagement. This was confirmed in a qualitative study in China where a fatalistic view had a positive influence on managing the challenges of cancer (Cheng et al., 2013). Another cross-sectional study in the USA, assessing coping strategies associated with psychological adjustment to advanced breast cancer, found no association between mood disturbance and 'fatalism' (Classen et al., 1996). Differences in culture could be an explanation for such disagreements. In our study we cannot conclude whether 'fatalism' would help with better psychological adjustment in later stages; however, the quantitative results revealed that the level of 'anxious preoccupation' decreased over time. It seems that taking more 'fatalism' mental adjustment was accompanied by decreasing 'anxious preoccupation'.

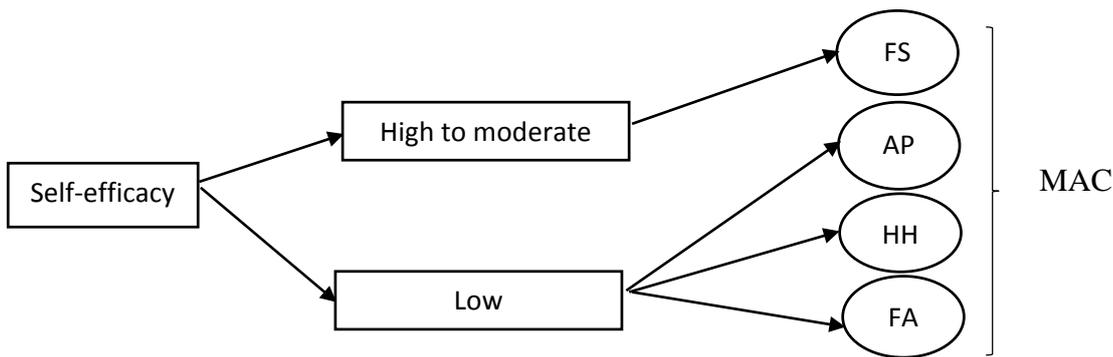
**Mental adjustment to cancer changes over time:** Using a longitudinal and mixed methods design, a statistically significant decrease was found for 'anxious preoccupation' over time as well as a clinical decrease for 'hopelessness/helplessness', 'cognitive avoidance' and 'fighting spirit'. The qualitative results suggested that participants were more likely to report a 'fatalism' over time. Many studies has tracked cancer patients' mental adjustment changes over time, and a steady adjustment progression has been suggested by some (Heim et al., 1997; Helgeson et al., 2004; Johansson et al., 2011; Nordin & Glimelius, 1998). Nordin and Glimelius (1998) found only minor changes of emotional well-being and coping strategies among 139 newly diagnosed GI cancer patients in Sweden over time particularly among non-cured patients. In the cured group, there was a decline in 'fatalism' between diagnosis time and 6 months after. An explanation for this difference with our findings could be that most participants expressed an uncertainty after surgery and chemotherapy, and they were not sure whether they were cured. Another study in Sweden, using a longitudinal design on 95 patients with laryngeal

cancer, demonstrated a decreased use of ‘anxious preoccupation’, ‘hopelessness/helplessness’ and ‘fatalism’ over a 12 month period (Johansson et al., 2011), which except for ‘fatalism’, these findings confirm our results. Another study assessed a consecutive series of 87 patients aged 45-75 years prior to diagnosis of breast cancer and 8 weeks and 9 months after first follow-up in UK; they showed a slight decrease in levels of anxiety and a possible increase in levels of depression over time (Nosarti et al., 2002). This decrease in levels of anxiety is in line with our study which looks reasonable as participants had passed the initial phase of receiving diagnosis and treatments and they were coming back to their normal life. Furthermore, the participants’ positive appraisal and reappraisal led them to feel less anxious and hopeless, but they tended to accept passively and showed less willingness to face the condition actively. It could be interpreted that participants appraised cancer less seriously after completion of treatments. This is the same as Heim et al. (1997) who suggested that changes in coping reflects the changing demands in the course of the disease. Similarly, Couper et al. (2010) suggested that men with early prostate cancer report less deterioration in psychosocial adjustment over time. They assessed psychosocial distress in Australian patients with early and advanced prostate cancer at diagnosis time and 12 months later. They showed that both early and advanced prostate cancer patients reported reduced vitality and increased depression and anxiety 12 months later, but it was greater in the advanced group. In contrast, Grassi and Rosti (1996), studying psychiatric morbidity and adjustment to illness in 52 cancer patients for 6 years, reported that the prevalence of psychiatric disorders decrease overtime. Our findings showed a decrease in psychosocial distress in a 4-6 month period after receiving the diagnosis of colon cancer. All participants started mental adjustment from the diagnosis point towards pre-surgical and post-surgical periods, undergoing an adjuvant chemotherapy and awaiting to hear the word of ‘being disease-free’ or having a ‘recurrence’. It is expected that after completion of the treatments, they felt more relieved by showing less ‘anxious preoccupation’ and ‘hopelessness/helplessness’; however, they were trying to adjust to the uncertainty between ‘disease-free’ or ‘recurrence’ in a fatalistic view instead of a ‘fighting spirit’. They believed that this new situation went ahead and it is impossible to have any control over it. Overall, the findings showed that participants moved from adopting an ‘anxious preoccupation/hopelessness’ and ‘fighting spirit’ mental adjustment towards a ‘fatalism’ over time.

**Mental adjustment and socio-cognitive theory:** In the present study, we used socio-cognitive theory as a framework to explore mental adjustment to colon cancer. Although we assessed

constructs of SCT's correlations with mental adjustment categories at both time points of study, there were only few differences in these correlations over time which was outside the research questions. Overall, the results showed that the SCT's constructs were correlated with four categories of mental adjustment to cancer. The high levels of self-efficacy, optimistic outcome expectations, goal setting and enacting self-regulation efforts, and high perceived social support were helping participants to adopt a 'fighting spirit'. On the other hand, the low levels of self-efficacy, uncertain outcome expectations, difficulties in self-regulation and low perceived social support were leading to the 'anxious preoccupation' and 'hopelessness/helplessness' adjustment. The 'fatalism' was correlated with low levels of self-efficacy, optimistic and uncertain outcome expectations, enacting self-regulation efforts and low levels of perceived social support. These findings are in line with the SCT which believes that the dynamic interactions between behavioural, personal and environmental factors affect adjustment to chronic illnesses (Bandura, 1997). To our knowledge, there are no studies about mental adjustment to cancer in correlation with full concepts of SCT. In a meta-analysis, Graves (2003) suggested that using SCT-based interventions enhances improvement in overall quality of life for cancer patients. Similarly, Rogers et al. (2005) found an association between physical activity and SCT constructs during breast cancer treatment, thus suggesting theory constructs as potential mediators or moderators in interventions evaluation.

**-Self-efficacy:** According to Bandura's theory, self-efficacy is the confidence that individuals have in their ability to perform a task or behaviour and it is a core component of SCT. Patients' ability to manage the physical and psychological challenges of cancer can be managed through self-efficacy beliefs (Bandura, 1997). In this study, participants' adjustment to cancer were explored in correlation with self-efficacy as one of the impacting factors. Our qualitative findings showed that 'fighting spirit' is a more common mental adjustment strategy among participants who expressed higher levels of self-efficacy. In contrast, 'hopelessness/helplessness', 'anxious preoccupation' and 'fatalism' were reported by participants with low self-efficacy status. The quantitative results confirmed the correlation between greater levels of 'fatalism' with lower levels of self-efficacy as well. Participants who believed in their inner strength and felt more confident to control the situation expressed a 'fighting spirit' mental adjustment. They were more determined to fight illness and were dealing with cancer as a challenge; conversely, participants who appraised that they might not be able to manage this new tough situation were more hopeless and anxious and expressed a fatalistic view (Figure 6.1).



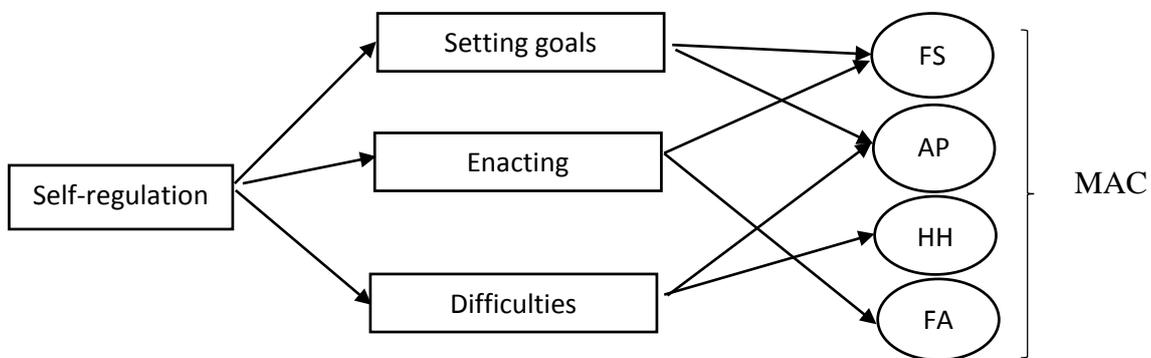
**Figure 6.1: The correlations between self-efficacy and mental adjustment to cancer categories**

*FS: fighting spirit; AP: anxious preoccupation; HH: hopelessness/helplessness; FA: fatalism*

The findings are confirmed by Bandura’s SCT which believes that a strong sense of efficacy is needed to face threats effectively. The SCT implies self-efficacy as a predictor for the experienced stress and depression related to coping with taxing environmental demands (Bandura, 1998). The findings are consistent with the previous studies that illustrated the correlation between self-efficacy and psychological adjustment to cancer (Beckham et al., 1997; Lev et al., 1999; Mosher et al., 2010; Mystakidou et al., 2013; Mystakidou et al., 2010; Nielsen et al., 2013; Philip et al., 2013; Qian & Yuan, 2012). Rottmann et al. (2010) investigated self-efficacy and mental adjustment among 684 breast cancer patients in Denmark over a 12 month period and reported that better self-efficacy predicts more active, approach-oriented adjustment style (more ‘fighting spirit’, and less ‘anxious preoccupation’ and ‘hopelessness/helplessness’). Phillips and McAuley (2013) confirmed that coping self-efficacy is an important predictor of patients’ adjustment among breast cancer survivors and it was a significant predictor of depression as well as a mediator between symptoms and depression. Similarly, Albrecht et al. (2013) assessed self-efficacy for coping with cancer in melanoma patients and found higher depression is predicted by lower self-efficacy coping with cancer. In the same way, Mystakidou et al. (2013) reported that higher general self-efficacy was related to less anxiety and more symptom severity but a better quality of life among patients with different types of cancer undergoing external beam radiotherapy. There are only a few studies that explore the relationship between fatalistic beliefs and self-efficacy in cancer patients. Straughan and Seow (1998) described a theoretical perspective on cancer ‘fatalism’ and

suggested that self-efficacy is influenced by ‘fatalism’. A study on Chinese women with hypertension showed that more control over health is related to greater self-efficacy (Chen, 1999). Therefore, our results about the relationship between self-efficacy and ‘fatalism’ is not surprising.

**-Self-regulation:** Participants described how they were trying self-regulating efforts to adjust to colon cancer. They reported more positive refocusing and acceptance over time, and ones who perceived adjusting to colon cancer disease as a task and set goals to manage this new situation reported ‘fighting spirit’ and ‘anxious preoccupation’ mental adjustment more frequently. These participants described cancer as a new task to deal with and the main goal was to get over it and get back to normal life. The findings also showed that participants who were enacting self-regulation efforts expressed ‘fighting spirit’ and ‘fatalism’. These participants reported that they have had to stop their usual leisure activities, they have been waiting for treatments and they have been asking help for their primary needs. In contrast, ‘hopelessness/helplessness’ and ‘anxious preoccupation’ were more common among participants who had difficulty in self-regulation for colon cancer. They expressed that it is not easy to stop usual activities, withdraw from their job and stick to the treatments (Figure 6.2).



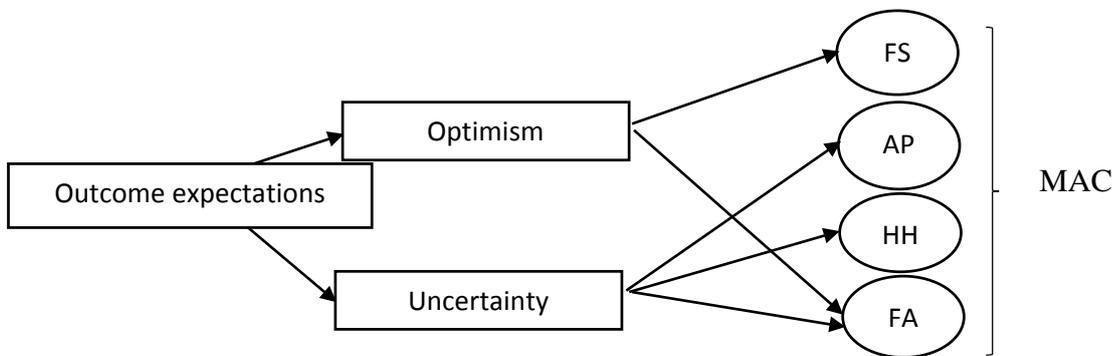
**Figure 6.2: The correlations between self-regulation and mental adjustment to cancer categories**

*FS: fighting spirit; AP: anxious preoccupation; HH: hopelessness/helplessness; FA: fatalism*

It is believed that self-regulation systems help adapting to threats via coping strategies (Leventhal et al., 1998). Self-regulation is one of the SCT's constructs which explains human agency and the influence of personal factors on behaviour and the environment (Denler et al., 2014). Therefore, it is expected to be correlated with more active coping strategies. Schroevers et al. (2008) studied the role of goal adjustment and emotion regulation strategies among 108 cancer patients in the Netherlands and found reengaging in meaningful goals and focusing on pleasant issues are significantly associated with more positive effects, whereas rumination and catastrophizing are significantly associated with more negative effects. These results are in line with our study; in particular, the quantitative findings which showed that high levels of other-blaming is correlated with high levels of 'anxious preoccupation' and 'hopelessness/helplessness', high levels of rumination is correlated with higher levels of 'anxious preoccupation' and 'cognitive avoidance', and high levels of catastrophizing is correlated with more frequent using of 'anxious preoccupation', 'hopelessness/helplessness' and 'cognitive avoidance'. The literature confirms that self-regulatory skills help individuals to anticipate, avoid and minimize stressful events. The basic process of self-regulation with social interactions and exceptional coping strategies come together as proactive coping (Aspinwall & Taylor, 1997). To our knowledge, there are no studies about the role of self-regulatory behaviours in mental adjustment to cancer, but some studies have shown a predictive role of self-regulation for coping in other situations. Lengua and Long (2002) examined self-regulation as a predictor of children's appraisal, coping styles and adjustment problems and found that self-regulation predicts more active coping and less adjustment problems. Our findings showed that when participants set goals to get over the cancer and get back to normal life, they adopt the 'fighting spirit' and 'anxious preoccupation' adjustment. Setting unattainable goals and uncertainty towards the future may be possible explanations for showing an 'anxious preoccupation'. The commitment to goals, accepting limitations and changing life style were related to 'fighting spirit' and 'fatalism'. Previously, the results showed that adopting 'fatalism' was accompanied by decreasing 'anxious preoccupation'. We can conclude that the self-regulatory behaviours help positive adjustment to cancer. On the contrary, appraising self-regulation as a hard and difficult task is accompanied by more 'hopelessness/helplessness' and 'anxious preoccupation' mental adjustment.

**-Outcome expectations:** Cancer patients appraise their cancer experience by positive or negative expectations. The negative expectations may limit using effective coping strategies and ability to adapt to disease (Graves & Carter, 2005). In the present study, we found that

optimistic expectations are linked to ‘fighting spirit’ and ‘fatalism’, whereas an uncertainty towards the future is responded to mostly by ‘anxious preoccupation’, ‘hopelessness/helplessness’ and ‘fatalism’. Furthermore, our quantitative results confirmed significant negative correlations between optimism with ‘hopelessness/helplessness’ and ‘fatalism’. Therefore, it seems that as long as participants showed optimistic attitudes towards cancer, they adopted “fighting spirit” adjustment strategy more frequently. Conversely, ‘uncertainty’ is accompanied by more negative mental adjustment such as ‘anxious preoccupation’ and ‘hopelessness/helplessness’. The correlation between outcome expectations and ‘fatalism’ was unclear and there were disagreements between findings; to our knowledge there is no literature which explains it (Figure 6.3).



**Figure 6.3: The correlations between outcome expectations and mental adjustment to cancer categories**

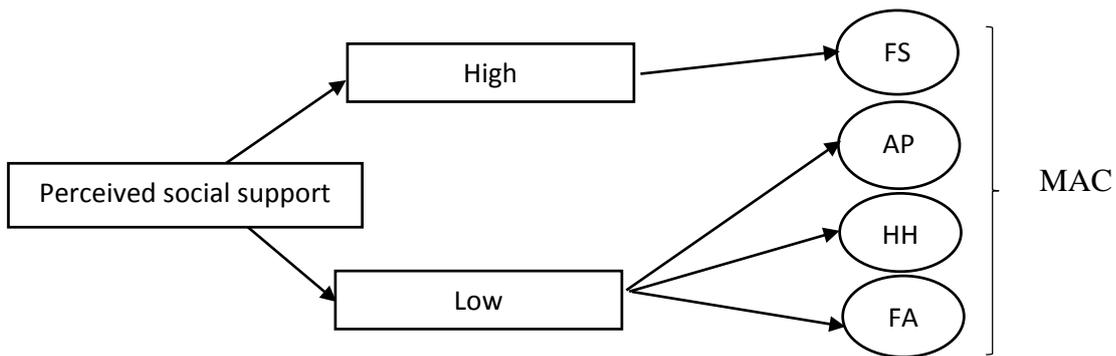
*FS: fighting spirit; AP: anxious preoccupation; HH: hopelessness/helplessness; FA: fatalism*

Excepting ‘fatalism’, the findings of the current study are consistent with Bandura’s socio-cognitive theory, which believes that positive outcome expectations result in health behaviour (Bandura, 1998). In addition, several studies have explored the role of outcome expectations in physical and mental health. Cohen et al. (2001) examined the association between treatment-specific optimism and mental health among American patients with metastatic renal cell carcinoma and melanoma, and showed that patients who believed that treatment would cure them and stop the progression report fewer symptoms of depression, lower mood disturbance and fewer symptoms of distress. Previously, Marks et al. (1986) had shown strong negative correlations between self-control/treatment expectations and depression.

In the qualitative analysis, we categorised participants' outcome expectations responses in terms of optimism and uncertainty. Optimism has been defined as the degree to which one expects positive outcomes in future (Scheier & Carver, 1985). A study on optimism and mental health outcomes among 158 patients with advanced cancer in US, has confirmed that optimism is significantly associated with fewer anxious and depressive symptoms and less hopelessness (Applebaum et al., 2014). Although the present study assessed early colon cancer patients, the findings are consistent with these results as we found a significant negative correlation between optimism with 'hopelessness/helplessness'. Very few studies have explored the correlation between optimism and mental adjustment to cancer. Hodges and Winstanley (2012) investigated effects of optimism and 'fighting spirit' on positive affect in cancer survivors in UK and found that optimism has a direct effect on positive affect in cancer survivors and 'fighting spirit' was also shown to be a significant mediator of this relationship. Optimistic expectations were linked to 'fighting spirit' in the present study. In the same way, literature has confirmed that more optimism is related to more problem-focused and adaptive copings, while less optimism is related to more avoidant copings (Lee & Mason, 2013).

In the present study, uncertainty was described in terms of an ambiguous future and the probability of recurrence after completion of the treatments. Being uncertain about outcome expectations was accompanied by 'hopelessness/helplessness' and 'anxious preoccupation'. Very few studies have addressed the effects of uncertainty on mental adjustment to cancer. Through a qualitative approach in Australia, Lobb (2014) explored strategies that 27 cancer patients with a prognosis of 12 months used to cope with the uncertain trajectory of their disease. The findings showed that patients coped with uncertainty through avoidance, maintaining a normal life, comparing themselves favourably to others in a similar situation and remaining positive. Another qualitative study exploring uncertainty and anxiety in cancer patients in UK found that the uncertainty engenders anxiety and frustration and exacerbates associated fears (Richardson et al., 2013). In spite of limited literature, our findings were not surprising because an uncertainty about outcome expectations may predict more distress among cancer patients.

**-Social support:** Findings showed that most high perceived social support participants report a 'fighting spirit'. In contrast, 'anxious preoccupation', 'hopelessness/helplessness' and 'fatalism' were shown by low perceived social support participants (Figure 6.4).



**Figure 6.4: The correlations between perceived social support and mental adjustment to cancer categories**

*FS: fighting spirit; AP: anxious preoccupation; HH: hopelessness/helplessness; FA: fatalism*

Many studies have indicated the association between a high level of perceived social support and better adjustment to cancer (Akechi, Kugaya, et al., 1998; Cicero et al., 2009; Grassi et al., 1993; Helgeson & Cohen, 1996; Inoue et al., 2003). According to SCT, social environment is a factor which affects the behaviour and it can be described as family members, friends and colleagues (Bandura, 2001). Participants who reported high perceived social support described that social connecting (marriage, friendship or membership in religious groups) were helpful to manage their new situation in terms of empathy and caring, offering service or even companionship. A ‘fighting spirit’ among participants with high perceived social support is in line with previous literature which confirms the role of social support in a better mental adjustment to cancer. Cicero et al. (2009) examined whether patients’ perceptions of social support predicts adjustment to cancer among 96 cancer patients in Italy. They found that perceived support from friends may predict the patient’s tendency to consider cancer as a challenge and to take an active role in the cancer journey. Similarly, Akechi, Kugaya, et al. (1998) assessed 455 ambulatory cancer patients in Japan and suggested that if the patient is living with others, it is correlated with ‘fighting spirit’, although marital status is not. More equally to our results, Grassi et al. (1993) suggested that perception of support from the individual’s ties may influence a better mental adjustment to cancer, particularly the patient’s ‘fighting spirit’, while an opposite association was shown for ‘helplessness’ and ‘fatalism’.

In the present study, participants who expressed a perception of low social support expressed an unwillingness to get others emotionally involved in their disease, some family problems and avoiding social contacts because they do not like others’ empathy. ‘Anxious preoccupation’, ‘hopelessness/helplessness’ and ‘fatalism’ were more common mental adjustment responses

among these participants. Eom et al. (2013) investigated the association between perceived social support and depression among 1,930 cancer patients in Korea and found that cancer patients with low perceived social support report significantly higher levels of depression, and social support has a direct effect rather than a stress-buffering effect. Similarly in the US, a longitudinal study assessing 154 women diagnosed with first occurrence of breast cancer suggested a significant curvilinear relationship between social support and distress at two time points of 3 weeks after surgery and 8-16 months later, and between social support and adjustment 8-16 months later (Mallinckrodt, Armer, & Heppner, 2012). However, Deno et al. (2012) investigated the mediating effects of social support among head and neck cancer outpatients with facial disfigurement which suggested that self-efficacy might be a mediator between social support and emotional distress, and that different sources of social support might play different roles in this mediation.

As expected, differences in mental adjustment to cancer were correlated with perceived social support. A 'fighting spirit' is evident in cancer patients with a high perceived social support, while low perceived social support ones are more prone to 'hopelessness/helplessness', 'anxious preoccupation' and 'fatalism'. It seems that social support connections may help positive adjustment to cancer by decreasing distress and moving from a passive acceptance towards taking an active role to fight illness.

### **Limitations of the current study**

Several limitations of the present research should be noted. A number of limitations were identified in relation to applying the methodology of mixed methods research. The pilot study showed that there were not sufficient time and samples to cover an extensive quantitative data collection. Under these circumstances an embedded qualitative strand within a quantitative part was chosen. The major challenge of mixed methods research is the lack of uniformity and absence of clarity as to when and at what level they are mixed (Sandelowski, 2003). Using mixed methods can be difficult and it requires skills in several areas, and the researcher needs to convince others of the value of mixed methods (Creswell, 2011). For this mixed methods research, quantitative data was not sufficient to answer research questions and was considered as a support for the dominant in-depth qualitative part. A longitudinal design was used to track the changes over a 6 month period at 2 time points, after surgery at first appointment at outpatient Oncology clinic, and 4-6 months after surgery. However, participants tried to recall their feelings and coping strategies immediately after receiving diagnosis of cancer and surgery

as well. Hence, the recall bias can be noted, as with other limitations of this study, as it is considered as a major threat to the internal validity of studies which use self-reported data (Hassan, 2006). A further limitation relates to the degree of attrition at time two leading to a possible bias. Moreover, limitations exist with the small sample size and non-probability sampling technique. Particularly, the small number of subjects in the quantitative part calls for caution in drawing statistical conclusions. The study sample for this mixed methods research was recruited through purposive sampling colon cancer patients who attended an out-patient oncology clinic in New Zealand and had undergone surgery. To promote the principles of minimising harm and distress, patients who were too distressed about cancer and its treatments were excluded from study. Thus, the study sample may reflect a group with a lower distress level than the average population; this limits the capacity to generalize findings to the larger population of newly diagnosed colon cancer patients. All participants in this study were New Zealand European with a new diagnosis of colon cancer; the extent to which these findings generalize to patients with other cancers, and other racial and ethnic groups is unknown.

Furthermore, we based our claims on participants' self-reports of their mental adjustment to cancer; more clinically based assessment might reveal different patterns of adjustment. Self-presentation biases, such as expressing 'good' or well-adjusted' are common in self-report measures and necessitates generalising with caution (Park et al., 2008).

Moreover, there may be other factors that affect mental adjustment to cancer that we could not assess in our study. The other stressful life events may have occurred before or after follow-up which affected participants' levels of distress. The other psychological variables could have distinguished mental adjustment responses. Our study is also limited in that we assessed only two time points in a very complex process of mental adjustment that begins at or prior to the point of diagnosis of cancer and extends through primary treatment and beyond to having a disease-free status or recurrence; therefore, more multiple assessments starting closer to diagnosis may be able to effectively explore mental adjustment and changing over time.

There are also limitations associated with the qualitative part of the research. The research questions in content analysis are ambiguous and too extensive; excessive interpretation poses a threat to successful analysis, even though it applies to all qualitative analysis (Elo & Kyngäs, 2008). The directed content analysis has some inherent limitations in that the researcher collects data with an informed and strong bias. Therefore, supportive evidence is more likely rather than unsupportive. Moreover, participants might get cues to answer interview questions

such as is suggested in Watson's mental adjustment categories even though they did not experience them. Using the rigid pre-determined categories did not allow for the wider story to come through. The directed approach can blind the researcher to contextual aspects of the phenomenon by overemphasising the theory (Hsieh & Shannon, 2005).

In conclusion, results from this study are individualised based on participants' characteristics and the situations they were experiencing; they are not able to be generalised to other groups dealing with particular types of cancer.

### **Strengths of current study**

The main strength of the present study was using a mixed methods research by employing a quantitative method to improve the findings relationship among variables in the embedded dominant qualitative part. Using both qualitative and quantitative approaches to answer exploratory questions provides stronger inferences and offers a greater assortment of divergent views (Teddlie & Tashakkori, 2009).

The other strength of this study was developing research within Bandura's social-cognitive theoretical structure which offered an explanation of mental adjustment to cancer through the concepts of self-efficacy, outcome expectations and self-regulation. This theory is one of the non-nursing theories that has frequently been used in nursing (Polit & Beck, 2013).

A further strength of this study was its longitudinal design which allowed the researcher to track changes of mental adjustment over time. Moreover, the study group was designed to be relatively homogenous by focusing on newly diagnosed colon cancer patients who had completed their surgical care and been referred to oncology for consideration of chemotherapy. In this respect they were a uniform group and possible complexity was accommodated.

### **Implications for future research**

Our findings suggest several implications for future research. Firstly, more research is needed to determine the role of each mental adjustment category in emotional recovery and a better quality of life. Another need involves efforts to better describe the goal of mental adjustment to cancer, such as getting back to pre-diagnosis functioning or defining a standard normality for cancer survivors. There is also a need to explore mental adjustment to advanced cancer with poorer prognosis.

More research is needed to explore mental adjustment to cancer changes at multiple time points especially at diagnosis time. It would be better for studies on adjustment to cancer to be guided by theory, and the social-cognitive model which we used as an underpinning framework offers a cognitive, behavioural and social pathway to help a better understanding of mental adjustment to cancer.

In addition, although we explored each construct of SCT correlations with mental adjustment to cancer, it would be useful to examine how the full concepts of SCT may help a better adjustment. The SCT offers ideas for designing further studies to explore predictors of positive adjustment which improve the quality of life. Furthermore, research might focus on reinforcing self-efficacy, social supports and self-regulation strategies which may facilitate adjustment.

### **Implications for practice**

Findings from this study suggest that after receiving diagnosis of colon cancer ‘anxious preoccupation’ and ‘hopelessness/helplessness’ are common. This may have important implications for both the cancer screening policy and the health care system. After having diagnosis of cancer, the main focus was planning a surgery while there was a remarkable need for emotional support. It seems clear that both physicians and nurses need to pay attention to the patient’s psychological status at diagnosis time, and the psycho-oncology services should be organised to help at-risk patients. The policy-makers should allocate staffing resources for psychosocial care similar to many cancer clinics which offer psycho-oncological services to vulnerable patients (Linden et al., 2012).

Furthermore, the results suggested that high levels of anxiety before surgery are mostly related to ‘surgery information need’ because of the unknown extent and aggressiveness of the disease. A preoperative information session with a nurse may help patients to feel being seen, secured, trusted, responsible and participating (Aasa et al., 2013). However, our findings showed that patients are satisfied with post-operative care of New Zealand health care services which should be encouraged to achieve a high level standard. Therefore a few weeks after surgery, the findings indicated that in spite of suffering symptom distress and functional decline, participants appraise their recovery and surgery result positively. Hence, the ‘fighting spirit’ was the most commonly used mental adjustment strategy at this time and an optimistic view was helpful for a better adjustment. Therefore, it is suggested to improve positive mental adjustment through offering a high standard health care system, as satisfaction with health

professionals especially physicians is beneficial to cancer patients for better coping (Akechi, Kugaya, et al., 1998).

Based on our results, it seems that taking more ‘fatalism’ mental adjustment in the New Zealand context is accompanied by decreasing ‘anxious preoccupation’. Accordingly, in planning psychosocial support for New Zealand cancer survivors, it may be helpful to view ‘fatalism’ as a positive aspect for mental adjustment to cancer, but it may be interpreted that cancer patients appraise less seriousness of cancer after completion of treatments 4-6 months after surgery. It may be an implication for the importance of psycho-oncology follow-up and encouraging ‘fighting spirit’ instead of adopting a fatalistic view.

Furthermore, our findings showed that ‘fighting spirit’ is a more commonly used mental adjustment among colon cancer patients who expressed higher levels of self-efficacy. Therefore, self-efficacy should be enhanced to improve mental adjustment to cancer and emotional well-being. Patients with poorer self-efficacy need to be recognized and supported by psycho-oncology services. It may be useful to focus on cancer patients’ empowerment and to target self-efficacy in the rehabilitation settings for cancer patients (Rottmann et al., 2010). Ongoing support is suggested even long after treatments to improve cancer survivors’ self-efficacy for a better mental adjustment to cancer.

Additionally, we found that the self-regulatory behaviours help positive adjustment to cancer. On the contrary, appraising self-regulation as a hard and difficult task is accompanied by more ‘hopelessness/helplessness’ and ‘anxious preoccupation’. It is suggested to organize intervention programs aimed at helping cancer patients to set attainable goals and adjust to new life after cancer. The professionals should recognize resources which enable cancer patients to set new goals and engage in the task of self-regulation efforts. The self-regulatory skills help individuals to anticipate in the occurrence of stressful events and enable people to minimize their impact (Aspinwall & Taylor, 1997).

Moreover, we found that the optimistic expectations are linked to ‘fighting spirit’ mental adjustment. It is suggested that cancer patients be helped to accept their situation realistically and learn to be content and trust health professionals to keep disease under control through treatments. Conversely, being uncertain about outcome expectations was accompanied by ‘hopelessness/helplessness’ and ‘anxious preoccupation’. As a result, cancer patients should be encouraged to keep their follow-up visits, and learn what they can do for their health and

what services are available to help them. Expressing feelings of fear or uncertainty with friends, family and professionals might be helpful to overcome uncertainty.

Finally, the findings showed that high perceived social support is correlated with a 'fighting spirit' while low perceived social support is linked to more use of 'anxious preoccupation', 'hopelessness/helplessness' and 'fatalism'. Admittedly, psychosocial supports should involve family and friends, improve communication and encourage both patients and family members to express needs and feelings. The patient-spouse relationship should be addressed to help a better adjustment. Moreover, the emotional support from physicians may help cancer patients' feeling of control and receive the information they need (Helgeson & Cohen, 1996).

## **Conclusion**

The focus of this thesis was to explore mental adjustment to colon cancer and changes over time in correlation with constructs of Bandura's socio-cognitive theory. The use of mixed methods and a longitudinal design generated a broad and deep understanding of how mental adjustment changed from receiving diagnosis of colon cancer to planning and recovering from surgery, deciding to start an adjuvant chemotherapy and experiencing its side effects and being called as a cancer survivor. The underpinning theory provided constructs of self-efficacy, outcome expectations, self-regulation and social support to be explored in relationship with mental adjustment to cancer.

The mental adjustment to colon cancer was shown to be constantly changing. At the initial phase of receiving diagnosis of colon cancer, the ongoing mental adjustment process was started by higher levels of 'anxious preoccupation', 'hopelessness/helplessness' and 'cognitive fighting spirit', changing to greater levels of 'active fighting spirit' 3-4 weeks after surgery and moving towards an increased levels of 'fatalism' 4-6 months after surgery. In other words, newly diagnosed colon cancer patients felt more relieved after diagnosis time and completion of the treatments by reporting less 'anxious preoccupation' and 'hopelessness/helplessness'; however, to adjust to the uncertainty as a cancer survivor, they expressed a 'fatalism' instead of a 'fighting spirit'.

High levels of self-efficacy were shown to be correlated with using more 'fighting spirit' in contrast to low self-efficacy status, which was related to 'hopelessness/helplessness', 'anxious preoccupation' and 'fatalism'.

The optimistic outcome expectations were accompanied by using more 'fighting spirit', while an uncertainty toward future was responded to mostly by 'anxious preoccupation', 'hopelessness/helplessness' and 'fatalism'.

There were several self-regulation efforts to adjust to cancer. The positive refocusing and acceptance increased over time and colon cancer participants who perceived their disease as a task and set goals to manage the situation and enacted self-regulation efforts reported more use of 'fighting spirit'. In contrast, 'hopelessness/helplessness', 'anxious preoccupation', and 'fatalism' were more common among participants who had difficulty in self-regulation for colon cancer. The self-regulation responses, such as reported other-blaming, rumination and catastrophizing, were correlated with more frequent use of 'anxious preoccupation', 'hopelessness/helplessness' and 'cognitive avoidance'.

The high perceived social support was shown to be correlated with 'fighting spirit'. On the contrary, the 'anxious preoccupation', 'hopelessness/helplessness' and 'fatalism' were shown by low perceived social support participants.

Despite the limitations inherent within the study, this research has contributed to knowledge of mental adjustment to colon cancer changes over time through a socio-cognitive approach. The results have significant implications for healthcare policy-makers to allocate psycho-oncological services to assist newly diagnosed cancer patients for a better mental adjustment.

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## **Appendices**

## Appendix 1

### Pilot study ethical application letter



15 November 2013

Dear Gary,

Please find attached an application for a pilot study as advised by the ethics committee. This will allow me to explore any issues related to data collection. I have addressed the points raised by Kate Reid in her peer review of my proposal below.

- 1- In consultation with my supervisors, I will no longer conduct interviews with participants. Participants will be asked to complete questionnaires only. This will reduce the amount of time participants would be engaged with the study and also potential distress.
- 2- Bandura's social-cognitive theory has been chosen to underpin this study. It is a learning theory that models how people learn to adjust to new conditions. In social cognitive theory, people are seen as self-organizing, proactive, self-reflecting, and self-regulating rather than as simply reactive organisms shaped by environmental forces or driven by basic inner impulses. For Bandura, introspection is critical to predicting the influence of environmental outcomes on behaviour as introspection is the mechanism by which people make sense of their psychological processes. Thus, social cognitive theory proposes that human functioning is the product of reciprocal determinism, or the dynamic interplay of (a) personal factors (e.g., cognition, affect); (b) behaviour; and (c) environmental influences, which interact to influence human behaviour (Bandura, 1986). The social cognitive theory (SCT), explains how people acquire and maintain certain behavioural patterns, while also providing the basis for intervention strategies (Bandura, 1997). Evaluating behavioural change depends on the factors environment, people and behaviour. The interactions of the individual with the environment are influenced by his or her cognitions and beliefs about ability, expectations of behavioural outcomes, and evaluation and modification of behaviour toward specific goals. Bandura (1986) categorized these influences into perceived self-efficacy, outcome expectations, and self-regulation, respectively. Treatments and interventions based on SCT theory are effective in increasing and even maintaining positive health behaviours. This positive change for cancer patients is often described as improved quality of life.

- 3- As a researcher and an oncology nurse, I acknowledge that participants are likely to be experiencing distress related to a recent diagnosis of cancer. In order to reduce the likelihood of increasing distress an experienced oncologist (second supervisor) and nursing staff from the surgery ward will identify and initially approach potential participants. The researcher will be present when participants complete the questionnaires. If any participants experience distress during the completion of the questionnaires, they will be reminded that they can stop filling these in and either complete at a later date or withdraw from the study without any impact on their current care. Anyone who becomes distressed will be encouraged to seek support from the person they feel is most appropriate and this may be the oncology department, their GP or the Cancer Society. I will offer each participant the contact details for the oncology department and the Cancer Society.
  
- 4- In reference to Kate's comment about the number of questionnaires, I have discussed this with my primary supervisor and we would like to seek feedback from participants on their experience of completing the questionnaires. Please see the additional questions that have been added to the questionnaire pack in order to gain this feedback.

I hope these explanations provide the information required.

Regards,

Shadi Sadat Safavi

PhD student

Centre of postgraduate nursing studies

University of Otago

Email: [sadsh627@student.otago.ac.nz](mailto:sadsh627@student.otago.ac.nz)

Associate Professor Lisa Whitehead

Primary supervisor

## Appendix 2

### Cover letter for ethical application



**Mr Gary Witte**

**28 April 2014**

**Manager, Academic Committees**

**Dear Mr Gary Witte**

Thank you for your feedback on the proposal entitled **'Adjustment to colorectal cancer following diagnosis: a socio-cognitive approach'**, Ethics committee's reference code: H14/057).

Please find your concerns addressed in the following points:

- 1- All newly diagnosed colorectal cancer patients are referred to an Oncologist after surgery. In out-patients clinic the patient meets the Oncologist and the nurse to discuss follow up treatments. The list of all appointments will be reviewed by a research nurse at the clinic one week in advance and the times of appointments will be e-mailed to the researcher of this study. Either the Oncologist or the nurse will ask the patient whether they would like to meet the researcher. The researcher will be at the clinic to meet the patients after their meeting with the Oncologist and nurse. If the patients agree to meet with the researcher, the researcher will briefly explain the study and give them the information sheet and the consent forms with a pre-paid envelop to take home to read. If the patients are interested in participating in this study, they will send signed their consent form back. The researcher can also send the pack of questionnaires to the patients or she might contact the patient to arrange an interview. The Oncologist and the nurse are the first ones who see the patients at clinic and can assess if they think a patient might feel too distressed to participate in the study, if this is the case they will not suggest that the patient meets the researcher.
- 2- The second supervisor (a medical Oncologist), has advised the researcher that there is a chart of all medical-surgical interventions following the diagnosis of colorectal cancer. All non-metastatic colorectal cancer patients will undergo surgery. All patients who have lymph node involvement will be referred to out-patient oncology clinic to start chemotherapy. They might complete their chemotherapy between 4-6 months after surgery. On completion of treatment all participants will be followed up after 4 months following their first meeting. They will be invited to take part in the second part of data collection after completion of chemotherapy.

- 3- The main aim of this study is to track changes of mental adjustment to cancer overtime. The mental adjustment has been identified as a cognitive and behavioural response. It has got 5 dimensions: fighting spirits, helplessness/hopelessness, anxious preoccupation, fatalism and avoidance. This study aims to identify how these dimensions will be changed over time and how they are correlated with socio-cognitive theory constructs. So, we can conclude which dimensions lead to learning to live with this new situation better. The inclusion criteria for recruitment are non-metastatic cancer patients undergoing chemotherapy. We chose the out-patient oncology setting to access the appropriate sample. The non-metastatic colorectal cancer patients with a positive lymph nodes involvement will be referred to this clinic after surgery.
  
- 4- An embedded qualitative strand within a quantitative part has been chosen for this study. The purpose of choosing this design is to answer the same research questions by using both methods. The embedded qualitative design improves recruitment procedure. The pilot study has shown that there is not sufficient time and participants to cover an extensive quantitative data collection. Collecting and analysing qualitative data enhances the quantitative part. Both qualitative and quantitative data are collected concurrently.

I hope these explanations provide the information required.

Regards

Shadi Sadat Safavi  
PhD student  
Centre of postgraduate nursing studies  
University of Otago  
Email: sadsh627@student.otago.ac.nz

## Appendix 3

### Pilot study consent form



# **Adjustment to colorectal cancer following diagnosis: a social-cognitive approach (Pilot study)**

***Principal Investigator:***

***Associate Professor Lisa Whitehead***

***(lisa.whitehead@otago.ac.nz , 03-3643851)***

### **CONSENT FORM FOR PARTICIPANTS**

Following signature and return to the research team this form will be stored in a secure place for ten years.

**Name of participant:**.....

1. I have read the Information Sheet concerning this study and understand the aims of this research project.
2. I have had sufficient time to talk with other people of my choice about participating in the study.
3. I confirm that I meet the criteria for participation which are explained in the Information Sheet.
4. All my questions about the project have been answered to my satisfaction, and I understand that I am free to request further information at any stage.
5. I know that my participation in the project is entirely voluntary, and that I am free to withdraw from the project at any time and this will not affect any treatment that I receive now or in the future.

6. I know that as a participant I will be asked to complete a questionnaire on mental adjustment to cancer, and a questionnaire on personal and environmental factors (your ability to manage your feelings and situations, your expectations of outcomes and the social support you have).

7. I know that the questionnaires will explore mental adjustment to cancer and my ability to manage situations and my feelings along with my expectations of outcomes and the social support I have and that if the line of questioning develops in such a way that I feel hesitant or uncomfortable I may decline to answer any particular question(s), and /or may withdraw from the project without disadvantage of any kind.

8. I understand the nature and size of the risks of discomfort or harm which are explained in the Information Sheet.

9. I know that when the project is completed all personal identifying information will be removed from the paper records and electronic files which represent the data from the project, and that these will be placed in secure storage and kept for at least ten years.

10. I understand that the results of the project may be published and be available in the University of Otago Library and I agree that any personal identifying information will remain confidential between myself and the researchers during the study, and will not appear in any spoken or written report of the study .

11. I know that there is no remuneration offered for this study, and that no commercial use will be made of the data.

Signature of participant:                      Date:

Signature and name of witness:                      Date:

## Appendix 4

### Pilot study information sheet



## Participant Information Sheet

### **Study title:**

Adjustment to colorectal cancer following diagnosis: a social-cognitive approach (pilot study)

### **Principal investigator:**

**Name:** Lisa Whitehead

**Department:** Centre for Postgraduate Nursing Studies

**Position:** Associate Professor

**Contact phone number:** 03-3643851

### **Introduction**

Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with relatives or friends, before deciding whether or not to participate.

If you decide to participate we thank you. If you decide not to take part; your treatment will be not affected now or in future and we thank you for considering our request.

### **What is the aim of this research project?**

The diagnosis of cancer can have a significant impact. The purpose of this study is to explore the pattern of mental adjustment in people diagnosed with colorectal cancer. It is anticipated that the results from this study will help us to

find out what kind of coping strategies improve cancer patients' quality of life. This study is being undertaken as part of the requirements for a PhD in nursing. The study is being run from the Centre for Postgraduate Nursing Studies at the University of Otago, Christchurch, in collaboration with the Oncology Department in Christchurch. The researcher is an experienced nurse and academic in Iran.

### **Who is funding this project?**

The University of Otago supports this project.

### **Who are we seeking to participate in the project?**

People diagnosed with colorectal cancer attending the Christchurch hospital surgical clinics are invited to participate in this study.

We are looking to recruit people after surgery, 18 years of age or older and who are able and willing to complete questionnaires.

### **If you participate, what will you are asked to do?**

Should you agree to take part in this project, you will be asked to complete a questionnaire on mental adjustment to cancer, and a questionnaire on personal and environmental factors (your ability to manage your feelings and situations, your expectations of outcomes and the social support you have). It will take no more than 50 minutes to complete. The completion of questionnaires will be done either in the outpatient clinics at Christchurch hospital, the Centre for Postgraduate Nursing Studies or at your home whichever suits you best.

Please be aware that you may decide not to take part in the project and this will not affect any treatment that you receive now or in the future.

### **Is there any risk of discomfort or harm from participation?**

If you are feeling very worried, it is better that you do not participate. If you feel very upset while completing the questionnaires you are free to stop filling in the questionnaires and withdraw from the study. The researcher can advise anyone experiencing distress how to seek support.

### **What specimens, data or information will be collected, and how will they be used?**

The questionnaires will be securely stored and only the primary researcher and her supervisors will view your data. Data obtained as a result of the research will

be retained for at least 10 years in secure storage. Any personal information held on participants [such as contact details etc.,] will be destroyed at the completion of the research. The results of the research will be provided or be made available to participants when the project is completed. You will not be identified in the final write up.

The results of the project may be published and will be available in the University of Otago Library (New Zealand) and every attempt will be made to preserve your anonymity.

### **What about anonymity and confidentiality?**

All information that is collected about you during the course of the study will be kept strictly confidential. If you decide to take part in the study you will be given a study identification code (ID) and that ID will be used instead of your name or any other information from that point onwards so that your anonymity is assured.

### **If you agree to participate, can you withdraw later?**

You may withdraw from participating in this study at any time without any disadvantage to yourself. The study will not affect any treatment and care that you are receiving now or in future.

### **Any questions?**

If you have any questions now or in the future, please feel free to contact either:

**Name:** Shadi Sadat Safavi

**Position:** PhD student

**Department:** Centre for Postgraduate Nursing Studies at the University of Otago, Christchurch

**Contact phone number:** 03-3643851

**Name:** Associate Professor Lisa Whitehead

**Position:** Main supervisor

**Department:** Centre for Postgraduate Nursing Studies at the University of Otago, Christchurch

**Contact phone number:** 03-3643851

This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or email [gary.witte@otago.ac.nz](mailto:gary.witte@otago.ac.nz)). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

Appendix 5

Consent form



Adjustment to colon cancer following diagnosis: a social-cognitive approach

Principal Investigator:  
Associate Professor Lisa Whitehead  
(lisa.whitehead@otago.ac.nz , 03-3643851)  
Centre of Postgraduate Nursing Studies

**CONSENT FORM FOR PARTICIPANTS**

Following signature and return to the research team this form will be stored in a secure place for ten years.

Name of participant:.....

1. I have read the Information Sheet concerning this study and understand the aims of this research project.
2. I have had sufficient time to talk with other people of my choice about participating in the study.
3. I confirm that I meet the criteria for participation which are explained in the Information Sheet.
4. All my questions about the project have been answered to my satisfaction, and I understand that I am free to request further information at any stage.

5. I know that my participation in the project is entirely voluntary, and that I am free to withdraw from the project at any time and this will not affect any treatment that I receive now or in the future.
6. I know that as a participant I will be asked to complete a questionnaire on mental adjustment to cancer, and a questionnaire on personal and environmental factors (your ability to manage your feelings and situations, your expectations of outcomes and the social support you have).
7. I know that the questionnaires and interviews will explore mental adjustment to cancer and my ability to manage situations and my feelings along with my expectations of outcomes and the social support I have and that if the line of questioning develops in such a way that I feel hesitant or uncomfortable I may decline to answer any particular question(s), and /or may withdraw from the project without disadvantage of any kind.
8. I understand the nature and size of the risks of discomfort or harm which are explained in the Information Sheet.
9. I know that when the project is completed all personal identifying information will be removed from the paper records and electronic files which represent the data from the project, and that these will be placed in secure storage and kept for at least ten years.
10. I understand that the results of the project may be published and be available in the University of Otago Library and I agree that any personal identifying information will remain confidential between myself and the researchers during the study, and will not appear in any spoken or written report of the study .
11. I know that there is no remuneration offered for this study, and that no commercial use will be made of the data.

Signature of participant:                      Date:

Signature and name of witness:                      Date:

## Appendix 6 Participant information sheet



### Participant Information Sheet

**Study title:**

Adjustment to colon cancer following diagnosis: a social-cognitive approach

**Principal investigator:**

**Name:** Lisa Whitehead

**Department:** Centre for Postgraduate Nursing Studies

**Position:** Associate Professor

**Contact phone number:** 03-3643851

**Introduction**

Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with relatives or friends, before deciding whether or not to participate.

If you decide to participate we thank you. If you decide not to take part in; your treatment will be not affected now or in future and we thank you for considering our request.

**What is the aim of this research project?**

The diagnosis of cancer can have a significant impact. The purpose of this study is to explore the pattern of mental adjustment in people diagnosed with colon cancer. It is anticipated that the results from this study will help us to find out what kind of coping strategies improve cancer patients' quality of life. This study is being undertaken as part of the requirements for a PhD in nursing. The study is being run from the Centre for Postgraduate Nursing Studies at the University

of Otago, Christchurch, in collaboration with the Oncology Department in Christchurch. The researcher is an experienced nurse and academic in Iran.

**Who is funding this project?**

The University of Otago supports this project.

**Who are we seeking to participate in the project?**

People diagnosed with colon cancer attending the Christchurch hospital surgical clinics are invited to participate in this study.

We are looking to recruit people after surgery, 18 years of age or older and who are able and willing to complete questionnaires and possibly take part in a short interview.

**If you participate, what will you be asked to do?**

Should you agree to take part in this project, you will be asked to complete a questionnaire on mental adjustment to cancer, and a questionnaire on personal and environmental factors (your ability to manage your feelings and situations, your expectations of outcomes and the social support you have). It will take no more than 50 minutes to complete. You might be invited to take part an interview which takes no longer than 30 minutes. You will be asked to complete questionnaires and possibly an interview at these 2 time points:

- First meeting at clinic after your surgery
- 4-6 months after first meeting

The completion of questionnaires and interviews will be done either in the outpatient clinics at Christchurch hospital, the Centre for Postgraduate Nursing Studies or at your home whichever suits you best.

Please be aware that you may decide not to take part in the project and this will not affect any treatment that you receive now or in the future.

**Is there any risk of discomfort or harm from participation?**

If you are feeling very worried, it is better that you do not participate. If you feel very upset while completing the questionnaires or during interviews you are free to stop or withdraw from the study. The researcher can advise anyone experiencing distress how to seek support.

**What data or information will be collected, and how will they be used?**

The questionnaires will be securely stored and only the primary researcher and her supervisors will view your data. Data obtained as a result of the research will be retained for at least 10 years in secure storage. Any personal information held on participants [such as contact details audio tapes, after they have been transcribed, etc.,] will be destroyed at the completion of the research. The results of the research will be provided or be made available to participants when the project is completed. You will not be identified in the final write up.

The results of the project may be published and will be available in the University of Otago Library (New Zealand) and every attempt will be made to preserve your anonymity.

**What about anonymity and confidentiality?**

All information that is collected about you during the course of the study will be kept strictly confidential. If you decide to take part in the study you will be given a study identification code (ID) and that ID will be used instead of your name or any other information from that point onwards so that your anonymity is assured.

**If you agree to participate, can you withdraw later?**

You may withdraw from participating in this study at any time without any disadvantage to yourself. The study will not affect any treatment and care that you are receiving now or in future.

**Any questions?**

If you have any questions now or in the future, please feel free to contact either:

**Name:** Shadi Sadat Safavi

**Position:** PhD student

**Department:** Centre for Postgraduate Nursing Studies at the University of Otago, Christchurch

**Contact phone number:** 03-3643851

**Name:** Associate Professor Lisa Whitehead

**Position:** Main supervisor

**Department:** Centre for Postgraduate Nursing Studies at the University of Otago, Christchurch

**Contact phone number:** 03-3643851

This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or email [gary.witte@otago.ac.nz](mailto:gary.witte@otago.ac.nz)). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

## Appendix 7

### Demographic information

Thank you for your interest in participating in this research. Please answer all questions.

.....

**Q1: What is your current marital status?**

- Married       Divorced       Widowed       Separated  
 Never been married       A member of an unmarried couple

**Q2: What is the highest level of education you have completed?**

- High School not to year 13  
 High School completed year 13  
 some units at university or Polytech or similar  
 Bachelor's degree  
 Master's degree  
 Doctorate degree

**Q3: How would you describe your current employment status?**

- Employed       Unemployed       Student       Homemaker  
 Retired       Unable to work

**Q4: What is your household's total annual income for the most recent calendar year?(\$NZD)**

- Less than \$10,000       \$10,000 to \$29,999  
 \$30,000 to \$49,999       \$50,000 to \$69,999  
 \$70,000 to \$99,999       \$100,000 or more

**Q5: Which of the following best describes the area you live in?**

- Urban       Rural

**Q6: Is your home:**

- Owned       Rented       Other. Please state.....

**Q7: Which ethnic group do you belong to?**

- New Zealand European       Māori       Samoan  
 Cook Islands Maori       Tongan       Niue an

- Chinese  Indian  
 Other (such as Dutch, Japanese, Tokelauan). Please state.....

**Q8 : What, if any, is your religious preference?**

- Protestant  Catholic  
 Islam  Jewish  
 Other  
 No Preference / No religious affiliation  Prefer not to say

**Q9 : Who lives with you?**

- Husband or wife or partner  Children (No: )  
 Father  Mother  
 Sister (No: )  Brother (No: )  
 Others (No: ) Please state.....

**How many people, including yourself, are there in your household?**

.....people

## Appendix 8

### Demographic and disease information

*(To be filled by researcher)*

Q1: gender:

Male  Female

Q2: age:

18-29  30-39  40-49  
 50-59  60-69  ≥70

Q3: diagnosis:

Colon cancer  Rectum cancer

Q4: date of surgery: .....

Q5: Stage of disease (TNM) after surgery:.....

Q6: received treatment before surgery:

chemotherapy  radiotherapy

Q7: received treatments between surgery and 6 months after surgery:

chemotherapy  radiotherapy

## Appendix 9

### Mini-MAC Scale

A number of statements are given below which describe people's reactions to having cancer. Please circle the appropriate number to the right of each statement, indicating how far it applies to you at present. For example, if the statement definitely does not apply to you, then you should circle 1 in the first column.

	Definitely does not apply to me	Does not apply to me	Applies to me	Definitely applies to me
1. At the moment I take one day at a time	1	2	3	4
2. I see my illness as a challenge	1	2	3	4
3. I've put myself in the hands of God	1	2	3	4
4. I feel like giving up	1	2	3	4
5. I feel very angry about what has happened to me	1	2	3	4
6. I feel completely at a loss about what to do	1	2	3	4
7. It is a devastating feeling	1	2	3	4
8. I count my blessings	1	2	3	4
9. I worry about the cancer returning or getting worse	1	2	3	4
10. I try to fight the illness	1	2	3	4
11. I distract myself when thoughts about my illness come into my head	1	2	3	4
12. I can't handle it	1	2	3	4
13. I am apprehensive	1	2	3	4
14. I am not very hopeful about the future	1	2	3	4
15. I feel there is nothing I can do to help myself	1	2	3	4
16. I think it is the end of the world	1	2	3	4
17. Not thinking about it helps me cope	1	2	3	4
18. I am very optimistic	1	2	3	4
19. I've had a good life what's left is a bonus	1	2	3	4
20. I feel that life is hopeless	1	2	3	4
21. I can't cope	1	2	3	4
22. I am upset about having cancer	1	2	3	4
23. I am determined to beat this disease	1	2	3	4
24. Since my cancer diagnosis I now realise how precious life is and I'm making the most of it	1	2	3	4
25. I have difficulty in believing that this happened to me	1	2	3	4
26. I make a positive effort not to think about my illness	1	2	3	4
27. I deliberately push all thoughts of cancer out of my mind	1	2	3	4
28. I suffer great anxiety about it	1	2	3	4
29. I am a little frightened	1	2	3	4

## Appendix 10

### Self-Efficacy Scale

For each of the following statements, please circle the choice that is closest to how true you think it is for you. The questions ask about your opinion. There are no right or wrong answers.

	Not at all true	Hardly true	Moderately true	Exactly true
1. I can always manage to solve difficult problems if I try hard enough.	1	2	3	4
2. If someone opposes or is against me, I can find a way to get what I want.	1	2	3	4
3. It is easy for me to stick to my plans and accomplish my goals.	1	2	3	4
4. I am confident that I could deal efficiently with unexpected events.	1	2	3	4
5. Thanks to my resourcefulness and ability to figure things out, I know how to handle unexpected or unforeseen situations.	1	2	3	4
6. I can solve most problems if I invest the necessary effort.	1	2	3	4
7. I can remain calm when facing difficulties because I can rely on my coping abilities.	1	2	3	4
8. When I am confronted with a problem, I can usually find several solutions	1	2	3	4
9. If I am in trouble, I can usually think of a solution.	1	2	3	4
10. I can usually handle whatever comes my way.	1	2	3	4

## Appendix 11

### Revised Life Orientation Test (LOT-R)

Please answer the following questions about yourself by indicating the extent of your agreement. Be as honest as you can throughout, and try not to let your responses to one question influence your response to other questions. There are no right or wrong answers.

	Strongly disagree	disagree	neutral	agree	strongly agree
1-In uncertain times, I usually expect the best.	0	1	2	3	4
2-It's easy for me to relax.	0	1	2	3	4
3-If something can go wrong for me, it will.	0	1	2	3	4
4-I'm always optimistic about my future.	0	1	2	3	4
5-I enjoy my friends a lot.	0	1	2	3	4
6-It's important for me to keep busy.	0	1	2	3	4
7-I hardly ever expect things to go my way.	0	1	2	3	4
8-I don't get upset too easily.	0	1	2	3	4
9-I rarely count on good things happening to me.	0	1	2	3	4
10-Overall, I expect more good things to happen to me than bad.	0	1	2	3	4

## Appendix 12

### Cognitive Emotion Regulation Questionnaire

Everyone gets confronted with negative or unpleasant events now and then and everyone responds to them in his or her own way. By the following questions you are asked to indicate what you generally think, when you experience negative or unpleasant events.

	Almost never	Sometimes	Regularly	Often	Almost always
1. I think that I have to accept that this has happened	1	2	3	4	5
2. I often think about how I feel about what I have experienced	1	2	3	4	5
3. I think I can learn something from the situation	1	2	3	4	5
4. I feel that I am the one who is responsible for what has happened	1	2	3	4	5
5. I think that I have to accept the situation	1	2	3	4	5
6. I am preoccupied with what I think and feel about what I have experienced	1	2	3	4	5
7. I think of pleasant things that have nothing to do with it	1	2	3	4	5
8. I think that I can become a stronger person as a result of what has happened	1	2	3	4	5
9. I keep thinking about how terrible it is what I have experienced	1	2	3	4	5
10. I feel that others are responsible for what has happened	1	2	3	4	5
11. I think of something nice instead of what has happened	1	2	3	4	5
12. I think about how to change the situation	1	2	3	4	5
13. I think that it hasn't been too bad compared to other things	1	2	3	4	5
14. I think that basically the cause must lie within myself	1	2	3	4	5
15. I think about a plan of what I can do best	1	2	3	4	5
16. I tell myself that there are worse things in life	1	2	3	4	5
17. I continually think how horrible the situation has been	1	2	3	4	5
18. I feel that basically the cause lies with others	1	2	3	4	5

## Appendix 13

### Multidimensional Scale of Perceived Social Support

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

	Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree
1. There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2. There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
3. My family really tries to help me.	1	2	3	4	5	6	7
4. I get the emotional help and support I need from my family.	1	2	3	4	5	6	7
5. I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6. My friends really try to help me.	1	2	3	4	5	6	7
7. I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8. I can talk about my problems with my family.	1	2	3	4	5	6	7
9. I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
10. There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11. My family is willing to help me make decisions.	1	2	3	4	5	6	7
12. I can talk about my problems with my friends.	1	2	3	4	5	6	7

## Appendix 14: SF-12v2 Health Survey

This survey asks for your views about your health. This information will help you keep track of how you feel and how well you are able to do your usual activities. If you need to change an answer, completely erase the incorrect mark and fill in the correct circle. If you are unsure about how to answer a question, please give the best answer you can. Mark only one answer for each question.

<b>01. In general, would you say your health is:</b>	Excellent	Very Good	Good	Fair	Poor
	<input type="radio"/>				
The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?	Yes, limited a lot		Yes, limited a little		No, not limited at all
<b>02. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf</b>	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>
<b>03. Climbing several flights of stairs</b>	<input type="radio"/>		<input type="radio"/>		<input type="radio"/>
During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?	All of the time	Most of the time	Some of the time	A little of the time	A little of the time
<b>04. Accomplished less than you would like</b>	<input type="radio"/>				
<b>05. Were limited in the kind of work or other activities</b>	<input type="radio"/>				
During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?	All of the time	Most of the time	Some of the time	A little of the time	A little of the time
<b>06. Accomplished less than you would like</b>	<input type="radio"/>				
<b>07. Did work or activities less carefully than usual</b>	<input type="radio"/>				
<b>08. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?</b>	Not at all	A little bit	Moderately	Quite a bit	Extremely
	<input type="radio"/>				
These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...	All of the time	Most of the time	Some of the time	A little of the time	None of the time
<b>09. Have you felt calm and peaceful</b>	<input type="radio"/>				
<b>10. Did you have a lot of energy</b>	<input type="radio"/>				
<b>11. Have you felt downhearted and depressed</b>	<input type="radio"/>				
<b>12. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?</b>	<input type="radio"/>				

**Semi-structured interview questions:**

1- How have you been since your operation/ chemotherapy?

**Mental adjustment to cancer**

I'm interested in finding out how you feel about your diagnosis and how the events of the past few months have impacted on this.

2-How do you feel about the surgery/ chemo that you recently underwent?

3-How do you feel about your disease?

4-How have you adapted to your new situation?

**Self-efficacy** (the extent of the one's belief in one's ability to complete tasks and reach goals)

5-How do you believe in yourself to perform difficult tasks or cope with anything new?

**Self-regulation** (the process of planning/monitoring and changing one's behaviour)

6- Would you describe yourself as flexible and able to adjust yourself to achieve your goals?

**Outcome-expectations** (a person's expectations about the consequences of an action, being optimistic or pessimistic)

7-What do you expect in future? Would you describe yourself as generally optimistic or pessimistic?

**Social support**

Who has supported you/been there for you recently?

10- How have family, friends, health care system and professionals responded to your diagnosis and recent treatment?

**General health status**

11-Does your general health affect you carrying out your usual activities?

12- Is there anything you would like to add that would further help me to understand how you are adjusting to your diagnosis and treatment?