

**DEVELOPING STRATEGIES TO IMPROVE THE MANAGEMENT OF
CHRONIC ILLNESS**

**A Focus on Disability and Psychosocial Aspects in an Illness with an
Organic Cause (Cancer) and an Illness with a Non-Organic Cause (IBS)**

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ABSTRACT

Models of health care concentrate on acute conditions yet the major cause of disease burden is chronic illness. An emphasis on biomedical, as opposed to bio-psychosocial models, underestimates psychological disability and fails to explain burdens resulting from illnesses with no known organic cause. Topics explored were: quality of life, chronic and acute stress, emotion regulation, communication, support services, patient expectations, satisfaction with medical treatment, and health care seeking. Using grounded theory (Glaser, 1992) and active patient participation (Susman & Evered, 1978), the major objective was to develop strategies to improve the management of chronic illness.

Two groups were studied: 20 patients with an organic cause (cancer) and 21 patients with a non-organic cause (Irritable Bowel Syndrome). Using quantitative and qualitative measures, observational studies (N=29), interviews (N=41), focus groups (N=12), and a case study (N=10) were conducted. IBS patients reported greater disability (increased distress and reduced quality of life) than the cancer group and other chronic illnesses. Cancer patients showed impaired quality of life but they reported levels of distress up to 50% lower than the general population and 75% lower than another chronic illness group. Some cancer patients appeared to under-report levels of distress; however, when applying Pennebaker's (1997) written disclosure method, emotional expression was not uniformly associated with beneficial outcomes.

Interviews with IBS patients revealed that determinants of dissatisfaction involved a lack of acceptance and/or understanding of an IBS diagnosis and an expectation that consultants would find an organic cause. Cancer participants reported no need for participation in decisions concerning treatment. Evaluations of the quality of health services received were distinct from evaluations of the quality of care received by specialists. Fighting spirit and

positivity were linked with emotional inhibition and a lack of uptake of support services. Patients became more pro-active in seeking emotional and social support later in their illness experience. These findings were interpreted within the Conservation of Resources Theory (COR; Hobfoll, 2001; 1999; 1998).

Results in this study challenge public policy recommendations that focus on encouraging consumer participation in health care. Recommendations for intervention and future research with cancer patients focus on application of the COR theory. In IBS, patient education, improvements in communication and the adoption of Drossman's (1998) bio-psychosocial model are advocated. Finally, recommendations for improvements in methodology involve suggestions to incorporate quantitative and qualitative measures using longitudinal assessments with the grounded theory (Glaser, 1992) approach being an excellent methodological template.

DECLARATION

This thesis contains no material that has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text of the thesis.

I give consent to this copy of my thesis, when deposited in the University Library, being made available for photocopying and loan.

SIGNED: _____ DATE: _____

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1 BACKGROUND AND SCOPE OF THESIS

A ‘burden’ of chronic disease now rises to challenge us ...[and] ... we’re coming to realise, as the World Health Organisation has, that as long as the acute care model dominates health care systems, health care expenditures will continue to escalate, but improvements in populations’ health status will not.

Chew & Van Der Weyden, 2003, p. 229

1.1 Background Chronic Disease

According to the World Health Organisation (WHO, 2005), each year approximately 35 million deaths occur as the result of chronic disease. Many of these deaths occur in young and middle-aged populations with 15 million of these deaths occurring in populations under 70 years of age. In 2005, deaths from chronic disease more than doubled those resulting from infectious and communicable diseases (Prince, Patel, Saxena, Moj, Maselko, Phillips & Rahman, 2007). Chronic diseases such as heart disease, stroke, cancer, respiratory diseases and diabetes were the main causes of mortality. Cardiovascular disease was the leading cause of mortality accounting for 30% of total deaths with cancer, respiratory conditions and diabetes accounting for an estimated 22% and, other chronic diseases and injury related deaths accounting for almost 20% (WHO, 2005).

Increasing mortality from chronic disease (70%), as compared with communicable and infectious disease (30%), is not just a western phenomenon. In all developing countries, except sub-Saharan Africa where AIDS is the leading cause of mortality, chronic diseases are rapidly becoming the dominant cause of mortality (Prince et al., 2007). In fact, 80% of all deaths occurring as a result of chronic disease occur in low to middle income countries (WHO, 2005). These figures are in stark opposition to the view that ‘affluence’ is the sole factor responsible for the global rise in the incidence of chronic illness. Instead, the WHO (2005) attributes the growing incidence of chronic disease in developing countries to the

impact of globalisation, particularly urbanisation. For instance, the proportion of individuals living in urban areas in countries such as Africa, Asia and Latin America has risen from 16% to 50% in recent times (WHO, 2005).

1.1.1 Prevention of Chronic Disease: Reducing Mortality and Disability

As the urban spread continues throughout the world, the WHO (2005) suggests that mortality estimates will increase by 17% from 2005 to 2015 resulting in an estimated 41 million deaths. It has been recommended that at least 80% of heart disease, stroke and diabetes and 40% of cancer could be eliminated by encouraging individuals to make dietary and lifestyle changes (Epping-Jordan, Galea, Tukuitonga & Beaglehole, 2005). Authorities have set targets to reduce rates of death occurring from chronic conditions by an additional 2% over and above initial progress made by countries such as New Zealand, the United Kingdom, Australia, and Poland (Epping-Jordan et al., 2005). Based on these projections, it is estimated that 36 million deaths could be averted and that 500 million healthy years could be gained (WHO, 2005). For instance, in addition to ‘mortality’ and other economic indicators (e.g., health expenditure and losses in productivity), a common indicator of the burden of chronic disease is the disability adjusted life year (DALY). The DALY “... combines the number of years of healthy life lost to premature death with time spent in less than full health. One DALY can be thought of as one lost healthy year of life” (WHO, 2005, p. 39).

1.1.2 Non-Fatal Disease Burden

Even if significant reductions in mortality are achieved via preventative interventions, due to projected population growth, particularly in individuals aged over 70 years of age, millions of individuals will be disabled by chronic disease leading to unprecedented increases in total disease burden. The population of individuals aged over 70 years of age, of which many have several chronic conditions is estimated to increase from 93 million to 217 million in high income countries; and in middle and low income countries from 174 million to 813 million (WHO, 2005).

The impact of the major chronic diseases is expected to place extreme pressure on health systems throughout the world. By 2030, almost 70% of DALYs in developing countries will be attributed to chronic diseases of which a significant proportion will be accounted for by non-fatal chronic conditions such as psychiatric conditions and neurological disorders (Prince et al., 2007). In Australia, a survey conducted by the Australian Bureau of Statistics (ABS, 2006) reported that 77% of Australians were living with one or more chronic conditions (i.e., defined as a condition lasting longer than 6 months) and more than half of those individuals aged over 65 reported 5 or more chronic conditions (ABS, 2006).

Despite the growing recognition of the impact of some non-fatal chronic illnesses (e.g. psychiatric conditions and neurological disorders) on disease burden there are numerous conditions which individuals experience on a long-term (i.e., chronic) basis, yet these conditions are not routinely included in disease burden or health expenditure data. Examples of such conditions include fibromyalgia, chronic fatigue syndrome, pelvic pain syndrome, chronic pain, musculoskeletal disorders, and functional gastrointestinal disorders such as irritable bowel syndrome (IBS).

Other commentators collectively describe disorders where there is no known organic cause as a 'somatoform disorder'. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; American Psychiatric Association, 2000), the term 'somatoform disorder' applies to conditions where no known biological or physical cause of symptoms - as evidenced by doctor's examination and/or laboratory tests - can be identified. Rief and Sharpe (2004) suggest that whilst the term 'somatoform disorder' is not widely used by medical professionals, particular specialist disciplines apply their own label and describe such conditions as syndromes (e.g., chronic fatigue syndrome) or functional disorders (e.g., IBS).

Some commentators argue that treatment for such conditions is largely unnecessary as a failure to treat symptoms does not lead to further progression of disease states or death (Porcelli, 2004). Nevertheless, many of these conditions impact on total disease burden incurred as a result of losses in productivity due to high levels of absenteeism (Dean, Aguilar, Barghourt, Kahler, Frech, Groves et al., 2005) and frequent health care use results in high levels of expenditure (Spiegel, Kanwal, Naliboff, & Mayer, 2005). Prince et al. (2007) suggest that 15% of primary care consultations occur for conditions for which there is no known medical explanation and costs in the United States are estimated to be in the order of US\$256 billion dollars per year.

According to the Australian Institute of Health and Welfare (AIHW, 2007), total expenditure for health during 2000-2001 was \$60.9 billion dollars; \$49.2 billion was expended in relation to recurrent conditions whilst 11 billion was attributed to costs associated with chronic disease. According to these figures, recurrent conditions cost four times as much as those conditions defined as chronic diseases. Unfortunately, no information pertaining to the types of recurrent conditions accounting for almost 50 billion dollars is documented. Indeed, it is possible that some of this expenditure occurs as a result of somatoform or functional disorders.

1.1.3 Criticisms of the Dominant Health Care Model

It appears that in collecting data pertaining to health care expenditure and burden, priority is given to those conditions for which a disease state is identified (i.e. chronic disease) versus recurring conditions (i.e. chronic illnesses) whereby the aetiology may not be directly contributed to a specific pathogen or disease. An emphasis on disease as opposed to illness is undoubtedly an outcome of the application of the biomedical model of health care where the focus is on identifying disease and on reducing mortality (i.e., improving survival), not necessarily reducing disability (i.e., reducing distress, improving quality of life). Such an approach is likely to underestimate total disease burden resulting from recurring conditions

where no known physical abnormality is known. Thus, the actual total disease burden occurring as a result of chronic conditions may be significantly underestimated.

An aging and growing population coupled with projected shortages of health care workers has authorities concerned about an impending health care crisis (Smith, 2008; WHO, 2006). In preparation for such a crisis, criticism has been directed at the biomedical model (NSW Health, 2001). The biomedical model, evolving in the 19th and 20th centuries in response to growing epidemics involving infectious and communicable disease, has been criticised for its lack of efficiency when attempting to manage diseases and illnesses prevalent in the 21st century (Chew & Van Der Weyden, 2003). Urgent calls have been made by the World Health Organisation to work towards the development of more effective models (WHO, 2006).

A major criticism directed at the biomedical model is its focus on the presenting symptom(s) alone rather than considering the overall impact of the condition on the patients' wellbeing (NSW Health, 2001; Walker, Peterson & Millen, 2003). Moreover, because of its focus on identifying disease or pathology, people living with chronic conditions often take the same diagnostic test multiple times; are often functioning as their own patient record; and, face considerable frustration in accessing the range of services required (NSW Health, 2001).

1.1.4 Developing Effective Management Strategies: Australian Initiatives

In recent years, the provision of funding and the development of policy have focused on improving the ability of health care systems to manage chronic conditions. In 2000, the NSW government provided a \$45 million dollar package to develop new models of care to meet the needs of patients living with chronic illness (NSW Health, 2001)¹. In the NSW Government's Action Plan for 2001-2003 health professionals were encouraged to adopt innovative, integrative and coordinated approaches towards managing chronic illness. In this document,

¹ Note that within this report the term 'chronic illness' is used although the conditions for which the report focuses on are those described elsewhere as diseases (i.e. cardiovascular disease, cancer, respiratory disorders).

recommendations for change included: the development of a personal health record and care plan; improved communication between general practitioners and specialists; and, facilitating systematic links with additional services (NSW Health, 2001).

Other recommendations focus on building the capacity of patients to deal independently with their illness. Several commentators suggest that the most efficient way to manage chronic conditions is to offer education regarding self-management and to encourage patients to adopt a ‘consumer’ or ‘citizen’ attitude toward their medical care (Lorig, 1996). In this model of care, patients are encouraged to deal “... with the consequences of disease and not the physiological disease” (Lorig, 1996, p. 41). Other features of this model include shifting the focus away from prescription and adherence towards encouraging patients to take an active role in managing their condition. Lorig (1996) suggests that the key to successful adoption of this model involves “continual patient/health professional communication” (Lorig, 1996, p. 41).

Related initiatives focus on encouraging shared decision-making (SDM). In a review of initiatives developed to facilitate patient participation in decision making, McCaffery, Shepherd, Trevena, Juraskova, Barratt, Butow et al. (2007) suggest that few practitioners in Australia engage their patients in SDM. In their review, they identify several studies that attempt to identify impediments to the implementation of SDM though only one study has been conducted in Australia. In the studies conducted abroad, the focus has been on identifying barriers at the health system and/or health practitioner level (McCaffery et al., 2007). Currently, limited knowledge is available concerning patient level factors that may impede the success of SDM initiatives.

1.1.5 Evaluation of Initiatives

In New South Wales, 60 Priority Health Care Programs were introduced under the NSW Health care initiative, known as the ‘Chronic and Complex Care Program’. Specific programs

were developed for particular chronic diseases, including cardiovascular disease, cancer and respiratory disease. A number of other federal, state, and regional initiatives (e.g., ‘Enhanced Primary Care, Chronic Disease’) aimed to improve the capacity of general practitioners to manage chronic conditions (Proudfoot, Infante, Holton, Powell-Davies, Bubner, Beilby, et al. 2007) According to Proudfoot et al. (2007), such initiatives lack coordination and currently General Practice in Australia does not have the organisational capacity to implement such initiatives.

Hickie and McGorry (2007) review a number of programs that have emerged from federal government initiatives in Australia such as the ‘Sharing Health Program’ and the ‘Australian National Primary Care Collaboratives’. These initiatives focus on the development of structured health care management plans and the facilitation of shared care in the management of chronic illness. Shared care essentially involves a multi-disciplinary team approach to managing chronic illness. According to Hickie and McGorry (2007), uptake of such initiatives, again, has been limited and major barriers include: the number and complexity of initiatives, a lack of financial incentive, a lack of integration, and administrative burden.

In Australia, there are few published accounts of research that systematically evaluate the impact of chronic disease models on improving patient outcomes (Harris & Zwar, 2007). According to Harris and Zwar (2007), most of the federal government’s initiatives have not engaged practitioners and Australia is significantly behind countries such as the United Kingdom. Chronic disease models in the United Kingdom such as the ‘General Practice Quality and Outcomes Framework’ have proven effective in managing chronic illness (Campbell, Hann, Hacker, Burns, Oliver, Thapar et al., 2001; Sutton & McLean, 2006). Several studies report positive outcomes such as improved self-monitoring behaviours (e.g., improved exercise and diet, reduced smoking), biological outcomes (e.g., improved serum cholesterol and blood pressure); and, reduced health care expenditure (e.g., reduced doctor’s

visits and less use of emergency services) (Bodenheimer, Wagner & Grumbach, 2002; Campbell, Roland, Middleton & Reeves, 2005; Feachem, Sekhri & White 2002).

1.1.6 Summary of Limitations Relevant to Managing Chronic Illness in Australia

Chronic care models, at least in Australia, have evolved mainly in response to specific diseases such as coronary heart disease, cancer, and respiratory disorders. A lack of uptake of programs precludes a comprehensive assessment of the effectiveness of Australian initiatives designed to improve the management of chronic conditions. Whilst the biomedical model of health care has been criticised for its lack of efficiency in terms of treating and managing chronic illness, a comprehensive and suitable alternative has not been proposed in Australia. Instead, a range of recommendations focus on a limited range of issues, emphasising in particular a need for multidisciplinary care, shared decision making, and a consumer and self-management focus. Despite the increasing popularity of these terms among policy makers and academics the acceptability of such principles to the Australian public is largely unknown.

Discussions focus on attending to a whole person's needs, incorporating psychological and psychosocial needs. These ideas are consistent with Engel's (1977) bio-psychosocial model. For instance, in this model, illness is contrasted with disease and a systems approach, incorporating psychosocial aspects (i.e. psychological and social factors) is taken when understanding the development and impact of illness (McLaren, 1998). Yet, the extent to which shared care models address psychosocial needs is largely unknown. Recommendations for 'shared care', for example, tend to emphasise needs with respect to managing aspects of the physical disease (e.g. symptoms) and emphasise improved communication between specialist(s) and general practitioner(s) (NSW Health, 2001). Specific and detailed recommendations regarding how chronic disease models can assess, and address psychological and/or psychosocial issues are absent from health policy recommendations.

1.2 Background: Chronic Illnesses Studied

1.2.1 An Organic versus a Non-Organic Illness

Two chronic illnesses were studied in this thesis: cancer and IBS. In cancer, the illness is life threatening, the physical cause of the condition is known and physical treatment approaches are, in many instances, well established. In Australia, IBS is described as a functional disorder; it is a non-life threatening condition and currently there is no accepted physical or organic marker and no particular preferred pharmacological treatment. In both conditions, research suggests that psychosocial factors such as stress may play an important role in the onset, the progression, and/or the exacerbation of the illness (Drossman, 1998). Similarly, in both conditions high levels of distress and impaired quality of life exist (Blanchard & Scharff, 2002; Classen, Butler, Koopman, Miller, Di Miceli, Giese-Davis et al., 2001; Frank, Kleinman, Rentz, Ciesla, Kim & Zacker, 2002; Luscombe, 2000).

1.2.2 Chronic Illness Definition

Within this thesis, the term ‘chronic illness’ refers to chronic diseases (e.g., life-threatening diseases such as cancer) as well as non-life threatening conditions that individuals experience on a long-term (i.e. chronic) basis. “In Australia, there is a lack of an agreed general definition of what constitutes chronic disease or illness” (AIHW, 2005a, p.2). Nevertheless, the AIHW (2005a) endorse O’Halloran’s (2004) definition that defines chronic conditions as typically lasting longer than 6 months, have a pattern of recurrence, a poor prognosis, and impact on an individual’s quality of life. In contrast to chronic disease, chronic illness may include conditions for which there is no known physical or biological marker implicated in their aetiology. As noted previously, such chronic conditions are sometimes described as somatoform disorders and/or functional disorders such as IBS (Rief & Sharpe, 2004). Individuals living with chronic illness, like individuals living with chronic disease, experience symptoms on a long term, and typically recurring, basis.

1.2.3 Cancer Definition and Overview of Incidence and Prevalence in Australia

Cancer is a diverse group of diseases in which some of the body's cells become defective, begin to multiply out of control, can invade and damage the tissue around them, and can also spread (metastasise) to other parts of the body to cause further damage. They are a large cause of mortality in Australia and also contribute much to morbidity and disability.

AIHW, 2006, p. 94

Direct health care expenditure for cancer is estimated at 2.7 billion dollars and comprises 5.7% of total health care expenditure (AIHWb, 2005). As at 2002, Australia had the fifth highest incidence of cancer in the world (AIHW, 2006). In 2004, 338,300 individuals (1.7% of the total population) were living with a malignant cancer (AIHW, 2006). In Australia in 2006, there were 106,000 new cases diagnosed; 60,600 males and 45,400 females (AIHW & AACR, 2007). Due to Australia's aging population, it is estimated that new cases will increase by 29% for men and 32% for women by the year 2011 (AIHWb, 2005). The most common form of cancer in Australia is non-melanoma skin cancer with approximately 374,000 new cases each year. In 2003, the types of cancer with the next highest incidence for males were prostate (13,526), colorectal cancer (5,679), melanoma (5,535) lung cancer (5,281), and lymphoma (2,297). For females, the highest incidence was for breast cancer (11,788) colorectal cancer (5,679), melanoma (3,989), lung cancer (2,968) and lymphoma (1,832) (AIHW & AACR, 2007).

1.2.4 IBS: Description of the Illness and Indices of Burden

Patients with IBS present to general practitioners, gynaecologists, and gastroenterologists with abdominal pain/discomfort, bloating, excessive wind and irregular bowel habits (Talley & Spiller, 2002). IBS affects an estimated 14 to 24% of women and 5 to 19% of men (Frank et al., 2002). A diagnosis of IBS is made on the basis of prescribed criteria as specified by the Rome or the Manning criteria (see Saito, Talley, Melton, Fett, Zinsmeister & Locke, 2003).

In both instances, adoption of the criteria in making a diagnosis of IBS involves extensive testing to eliminate positive/alarm symptoms such as life threatening conditions including cancer (Dancey, Fox & Devins, 1999). In other words, in the absence of any physical aetiology, as revealed by testing incorporating blood tests and colonoscopy, a 'functional' diagnosis is made. Whilst IBS is not associated with premature death, it is a chronic illness as management of symptoms is ongoing, and symptoms rarely resolve completely. In follow up studies, 95% of patients continue to experience symptoms 5 years after the initial onset of symptoms (Kay, Jorgensen & Jensen, 1994).

1.3 Overview of Thesis

1.3.1 Holistic Approach Adopted

Within this thesis, a holistic approach to the development of knowledge was emphasised. This is reflected in a number of ways throughout the thesis such as the approach taken in presenting the results of the research; the diversity and breadth of literature consulted; the range of psychosocial factors incorporated; the use of quantitative and qualitative data; the incorporation of a variety of research designs; the philosophical approach adopted when conducting the research, interpreting the data, proposing hypotheses and developing recommendations.

1.3.2 Psychosocial Factors and the Management of Chronic Illness: Justification and Rationale

At the present time, there are considerable gaps in knowledge concerning what might be best practice with respect to the management of chronic illness in Australia. Critically, major gaps exist in understanding the role of psychosocial factors in the management of illness.

Furthermore, a lack of research has focused on engaging the Australian community with respect to assessing the acceptability and perceived relevance of health policy recommendations.

Psychosocial factors explored in this thesis incorporated a focus on patient expectations, doctor-patient communication, quality of life, psychological distress, coping strategies, satisfaction with treatment, support services and health care use. A lack of focus on the role of psychological and psychosocial factors when proposing policy concerning improving the management of chronic illness may lead to a) a lack of uptake of public policy recommendations b) increased burden on the health system c) unaccounted for disease burden. For example, as discussed in Chapter 2, models of health care and disease burden estimates are based on physical aspects of the illness. Yet individuals living with chronic illness experience significant psychological distress and impaired quality of life (for reviews of literature see Chapters 2 & 3). Unresolved distress may result in increased use of health services (see Chapter 9) and may impact on total burden. For example, individuals with chronic illness may miss extended periods of time from work. Thus, losses in productivity may indirectly contribute to increased costs associated with chronic illness (see Chapter 2).

Furthermore, an emphasis on psychological and social research (i.e., ‘psychosocial research’) which incorporates research focusing on aspects of individuals (e.g., coping strategies) and social environments (e.g., engagement with others and social networks incorporating support services) is important when attempting to develop effective strategies to reduce burden occurring as a result of chronic illness. As reviewed, current health care models focus on a limited range of issues such as multi-disciplinary care or shared care. Current health care models and public policy recommendations do not incorporate an account of individual differences and how they might impact on the manner in which a patient copes with and/or adjust to living with a chronic illness. In addition, very little, if any, recognition is given to the role of a patient’s social network in facilitating adaptive coping responses to chronic illness.

Thus, in addressing these limitations and in attempting to develop a broad knowledge base concerning which factors may impact on the development of strategies to improve the management of chronic illness, this thesis aims to incorporate a breadth of literature including health policy, psychology, psychooncology, gastroenterology, and epidemiology. As well as attempting to understand the role of psychosocial constructs such as patient satisfaction with health care, patient expectations of care and quality of life, analysis of individual level factors are included in this thesis. For instance, within both samples, a particular focus on the psychological construct of distress was emphasised.

The presence of psychological stress has long been implicated with the development of chronic illness (see Chapter 3). In IBS, stress has been implicated in the onset and exacerbation of symptoms (see Chapters 2 & 9). Moreover, psychological distress has been linked with the development of cancer and diagnoses of recurrence (see Chapter 4). Within the cancer sample, a particularly strong emphasis was given to the constructs of distress and emotional inhibition. For example, an analysis of factors that may facilitate or impede adaptive reactions to a cancer diagnosis (i.e. emotional inhibition) may be important in understanding the total impact of disease burden (i.e. physical and psychological distress) that occurs as a result of cancer.

Indeed, the role of emotional inhibition in the development and/or progression of cancer has dominated the psychological literature for many decades. Thus, when viewing total health care as incorporating more than simply the absence of disease (see Chapter 2), strategies that attempt to improve chronic illness outcomes such as reducing distress should be important considerations when attempting to develop effective strategies to improve the management of chronic illness. For example, a failure to adapt to receiving a diagnosis of cancer may lead to increased use of mental health services. Alternatively, and in light of the evidence that links the experience of psychological stress with the development of a range of chronic illnesses

(see Chapters 2 & 3) a failure to acknowledge distress (i.e. emotional inhibition) may impact adversely on survival, or on the development of other chronic illnesses. Although, as is discussed in Chapter 2, the direction of causation between psychological distress and chronic illness has not yet been adequately addressed.

Nevertheless, within this thesis and when considering effective ways in which to improve the management of chronic illness, and given the emphasis on the emotional inhibition construct in the psychological literature, a focus on this construct was viewed as pivotal to providing a holistic understanding of how individuals adjust to and cope with a diagnosis of cancer. An extended critique of literature that focuses on constructs related to emotional inhibition and expression is provided in Chapters 4, 5 and 8. Constructs related to emotional inhibition include: suppression, repression and fighting spirit.

All data which form the basis of the research conducted for this thesis are presented in a series of six studies. The studies are not necessarily presented in the order that data were collected. Instead, the order of presentation reflects the evolution and development of knowledge that occurred as a result of the analysis and interpretation of data and consultation with the literature. For example, a shift in emphasis from individual constructs (e.g., fighting spirit, emotional inhibition) towards those incorporating the social system (incorporating health professionals) occurs following the findings reported in Chapters 1 through 5. Specifically, in Chapter 5, the complexities associated with individual level constructs are highlighted within a methodological and theoretical review

In presenting these studies, specific information concerning the participants are reviewed within each chapter. It is important to note though that these participants were drawn from two main samples. Throughout the course of the research, participants had different levels of involvement in the research. For example, whilst all participated in the interviews, others did

not attend focus groups held, return questionnaires, or participate in the intervention conducted.

Presented as follows is a synopsis of each study, incorporating a description of the main literature drawn upon, the methodology, research design and philosophical approach used. For example, in early stages of this research a traditional hypothetico-reductionist approach was used when reporting on the results based on questionnaire data. In later stages of the research, a shift in the unit of analysis from the individual level to one that incorporated the impact of others (e.g., family, friends and medical practitioners) on participants' illness experiences saw a change in methodological approach adopted.

1.3.3 Study 1 (see Chapter 2)

A review of epidemiological literature indicated a lack of data with respect to the impact of chronic illnesses for which there is no known physical cause. Similarly, a lack of information concerning the long term and ongoing impact on disease burden for cancer patients who have exited the acute stage of their treatment was evident. A review of research particularly in the cancer literature, but also the gastroenterological literature, indicated that standardised measures of quality of life are increasingly used to measure patients' perceptions of total disease burden (Mozaffari, Purpak, Pourseyed, Farhoodi, Agharmohammadi, Movahadi, et al., 2007).

Based on the review of literature presented in Chapter 2, it was predicted that higher levels of distress would be associated with lower levels of quality of life. Furthermore, it was predicted that both groups would have higher levels of distress, and more impaired quality of life as compared with general populations. An exploratory approach to comparisons between the IBS and cancer groups - and other chronic illnesses - was taken. For instance, no known prior research has compared levels of distress and quality of life in an illness with an organic

cause versus an illness without a known organic cause. This study used an observational design and involved the use of data collected via questionnaire (N = 29).

1.3.4 Study 2 (see Chapter 3)

Based on the research findings reported in Chapter 2, additional assessment of the nature of distress was performed in the cancer sample. Cancer patients' scores on some domains of the distress measure were considerably lower than scores reported in the general population and as compared with the IBS group, and another chronic illness group. In an effort to explain these findings, a review of theory that links stress with disease, and empirical studies that assess the impact of different kinds of stressors is presented. Also reviewed is literature which suggests that cancer patients experience an acute stress reaction, akin to a traumatic event, following the diagnosis of cancer. The focus of analysis in this study was on assessing the presence of traumatic stress symptoms and on ascertaining whether cancer patients in this sample reported levels of distress that were comparable with individuals exposed to other kinds of traumatic events. In addition, it was predicted that an acute measure of stress would be superior when predicting quality of life scores, as compared with a chronic measure of distress. In this study an observational design was used (N = 16).

1.3.5 Study 3 (see Chapters 4-5)

In Study 3, the role of emotional inhibition was explored as a potential mechanism that might explain the low levels of distress reported by cancer patients in Chapter 2. Literature in the psycho-oncology and psychology disciplines was reviewed. This review indicated that cancer patients show a tendency towards underestimating their levels of distress on self-report measures of distress compared with other chronic illness groups (for reviews see: Garssen, 2004; Giese-Davis & Spiegel, 2003; Kiecolt-Glaser McQuire, Robles, Walker, 2002; McKenna, et al., 1999). This finding has been linked with certain coping styles where there is a tendency to inhibit the expression of emotion; for example, repressive and/or suppressive styles of coping (Garssen, 2004). Indeed, within the cancer-coping literature, the concept of

emotional inhibition has received considerable attention. When reviewing this literature, it was evident that whilst distinct measures exist for repression and suppression, other measures of personality (e.g., Type C Personality; Temoshok and Fox, 1984) also claim to assess emotional inhibition. As well as assessing levels of endorsement on emotion regulatory measures and coping styles (e.g., Helpless/Hopelessness/Fighting Spirit; Greer, Morris & Pettingale, 1979) further aims of this chapter were to assess the extent of overlap among measures and to assess the degree that such measures predict psychological adjustment (i.e. distress and quality of life). An observational design was used and was based on data obtained via questionnaire (N=16).

In chapter 4, the results indicated very little overlap among measures of emotional inhibition and both emotional regulatory constructs (i.e. emotional expression and emotional inhibition) were associated with increased distress. These findings were contrary to theoretical propositions reviewed. Therefore, in Chapter 5 an extended discussion focuses on conceptual and theoretical issues concerning the measurement and factor structure of measures assessing emotional regulatory strategies, personality and coping styles. In the context of this thesis, this discussion was considered necessary because of the dominance of the concepts in the cancer literature and the implications such constructs may have for the design of interventions – and assessments of efficacy - aimed at reducing distress and improving quality of life. Thus, major aims of this discussion were to assess the extent to which current measures reflect a uni-dimensional construct (i.e. emotional inhibition) and to consider the validity and utility of such constructs when attempting to understand the cancer coping process and when developing strategies for reducing the psychological impact of cancer (i.e. reducing distress and improving quality of life).

1.3.6 Study 4 (see Chapters 6-7)

In Study 4, a shift from a focus on constructs based on individual level assessment is made. Instead, the unit of inquiry focuses on patients' communication experiences with

family/friends and medical professionals (N = 20). The semi-structured interview schedule included questions concerning patients' communication experiences; satisfaction with options concerning treatment; patient expectations, and the referral/uptake of psychological and community services. To complement this inquiry, results of a clinical interview that was based on identifying Axis 1 disorders, as described by the DSM-IV-TR (APA, 2000), are provided.

Glaser's (1992) grounded theory was used to guide the conduct of the interviews, the analysis, interpretation of results and the development of knowledge and recommendations. Grounded theory refers to the development of theory that is 'grounded' in the data produced from a study, or across a range of studies or observations (Crooks, 2001). Applications to public health issues are frequent, particularly in areas of health whereby biomedical accounts of health and illness fail to account for contextual factors (e.g., socio-cultural factors) (Crooks, 2001). A review of the approach along with details concerning its applicability and relevance to the development of knowledge in this thesis is provided in Chapter 6 (Fernandez, 2004).

It is important to note though at the outset that the incorporation of such an approach engenders a significant departure from traditional methods used in psychology and other scientific disciplines. For example, within the traditional hypothetico-reductionist framework, the literature informs the proposal of hypotheses and dictates the approach to testing these. In contrast, when applying grounded theory, the data produces the hypotheses and generally the literature is consulted considerably later in the process. When the literature is consulted, it is assessed in terms of whether it provides a full account of the data emerging from a study, or studies.

The results of this study are presented in Chapter 6. Reported in this chapter also are the results of a follow up study performed with cancer patients (N=10). Consistent with

Participatory Action Research (PAR; Elden & Chisholm, 1994; Kemmis & McTaggart, 2005; Susman & Evered, 1978), the aim of the follow up study was to engage participants in the research process. Specifically, participants were encouraged to assess the relevance and applicability of the results of the interviews and to propose recommendations. The PAR approach has been widely used to facilitate community development with respect to improving community health (Minkler & Wallerstein, 2003). The PAR approach is heavily influenced by Kurt Lewin's (1946) work that focused on the development of theory and research that impacted on the social system (i.e., producing change). Such an approach is known as Action Research (Khanlou & Peter, 2005). PAR extends upon Lewin's (1946) ideas and incorporates a focus on facilitating participation from social groups. According to Khanlou and Peter (2005), PAR is not so much a methodology as it is an orientation; that is, a way of looking at an issue – a philosophical stand point.

There are many derivatives of PAR and different applications and foci exist (Munn-Giddings, Hart & Ramon, 2005). In this study, the focus of PAR was on engaging patients (i.e. 'consumers') in the research process, and developing 'shared solutions' (Munn-Giddings et al., 2005) particularly in terms of working towards effective management strategies for dealing with chronic illness. This approach also enables application of a methodology that potentially reduces researcher bias. For example, in a typical application of the PAR methodology, results of research are fed back to participants and they are asked to comment on the extent to which the findings are applicable and/or relevant to their experiences. Such an approach requires that the researcher be forced to consider research findings which may not be consistent with their original assumptions.

In Chapter 7, the substantive codes (i.e., the emerging categories) reviewed in Chapter 6 are collapsed into higher order codes (i.e., theoretical codes). These include a focus on coping through communication – inhibition and positive spirit, evaluations of care, and coping and

support services. Within these main areas, explanatory models were developed. The aim of these models was to show the relationship among substantive codes and to propose hypotheses for future research, incorporating recommendations for intervention. For example, the results suggested that constructs such as emotional inhibition and positivity may be socially determined, not personally determined as is advocated in the formal literature. With respect to proposing hypotheses for future research within the broad category, 'evaluations of care', issues of participation in decision making and the role of patients' expectations are discussed with reference to public policy recommendations.

Results from the follow-up study resulted in new knowledge that contradicted some aspects of the interview results. Thus, in accord with principles of grounded theory (Glaser, 1992), existing psychological literature that could potentially explain the 'data' was reviewed. Via a process known as 'constant comparison' (see Chapter 5) the raw data (i.e. the interview data) were again consulted. Hobfoll's (2001; 1999; 1998) Conservation of Resources (COR) theory provided a complete account for the cancer coping process, incorporating the inconsistencies observed. Ultimately, Hobfoll's (2001; 1999; 1998) COR theory led to the proposal of recommendations focused on facilitating the use of community services and the development of resource caravans (see Chapter 10).

1.3.7 Study 5 (see Chapter 8)

In Study 5, cancer patients participate in a written disclosure intervention based on Pennebaker and Chung's (2007) most recent theory (e.g., the A to D Emotion Theory). A review of the majority of studies that have assessed the efficacy of emotion focused approaches, including Pennebaker's (1997; Pennebaker & Beall, 1986) written disclosure method, revealed that the majority of studies have focused exclusively on symptom reduction. It is argued that this approach has consequently limited the advancement of knowledge concerning 'why' the approach is therapeutic. Nevertheless, in two studies that did focus on the process of therapeutic change both report that the expression of some negative emotions

may be deleterious (Lieberman & Goldstein, 2006; Pennebaker 1997). These findings challenge the proposition that the expression of negative emotion alone (as is the emphasis in emotion focused approaches), is beneficial therapeutically and such claims may lead to inappropriate applications of therapies involving the expression of emotion.

Whilst outcome measures were included (i.e. distress and quality of life) the major aim of this study was to contribute to theory building concerning ‘why’ the therapeutic writing process assists in reducing emotional distress. Adopting a case study (N=10) longitudinal design (i.e. incorporating multiple measures across a 4 week intervention period), the focus was on assessing emotional regulatory processes (inhibition/expression) and contextual factors associated with writing (e.g., number and nature of emotion labels used).

1.3.8 Study 6 (see Chapter 9)

In Study 6, the focus is returned to IBS patients (N = 21). The emphasis was on patients’ experiences of their illness and on outcomes used to evaluate the quality of medical care. A mixed methods design, incorporating quantitative and qualitative measures, was used. Participants were required to anchor, on a Likert scale, their levels of satisfaction; the extent to which their concerns were addressed; the severity of pain experienced; and, the extent of impact of their symptoms on daily living. This quantitative data was complemented by a semi-structured interview that included questions that focused on developing a richer understanding of patient responses with respect to these particular domains. Whilst quantitative assessments were included, the philosophical approach was still based on grounded theory (Glaser, 1992). For instance, the research was patient focused and emphasised the generation of hypotheses rather the confirmation of *priory* hypotheses.

For example, in the gastroenterological literature, the main hypothesis proposed to account for increased health care use in IBS patients focuses on the role of psychopathology (Creed, 1997). However, it is argued that such a focus does little to improve the efficiency of health

care. Instead, best practice recommendations that focus on improving doctor-patient communication and understanding the role of patients' expectations are considered. Thus, whilst in this study a brief account of the literature is provided at the outset of the study and this informs the particular foci of the research (i.e. patient satisfaction and expectations), grounded theory is used to ensure the research reflected a valid 'phenomenological experience' from the patient's perspective, as opposed to the researcher's. Thus during the interviews the transcripts were constantly compared and contrasted for richness of data, and when new categories were identified, questions were added to the interview schedule. This approach identified a range of factors potentially implicated in increased health care use and resulted in the development of a model: The Health Care Utilisation Model. This model attempts to generate hypotheses concerning the health care use of IBS patients and suggests avenues for the development of interventions at the individual (i.e. patient) and service delivery levels.

As part of this study, an attempt to engage patients in the research process was made. Only 2/21 participants attended a focus group. As will be discussed in Chapter 9, patients in this chronic illness group were not at the point of accepting a 'consumer' or self-directed approach for managing their condition. Patients also appeared not to be ready for the application of a holistic model of health care. Implications of this research are discussed within the context of the dominant health care model (biomedical) and recommendations for improving the management of IBS focus on incorporating a bio-psychosocial approach to treating the illness. Significant impediments to such an approach are evident and impediments to its implementation are reviewed.

1.4 Recruitment and Sampling

Individuals representing each of the chronic illnesses studied were recruited via different methods. Thus, an overview of the recruitment and sampling methods is provided. With

respect to the cancer sample, significant variation in the research protocol occurred predominantly due to a lack of accrual, and changes in direction in early stages of this research. For example, initially the project was conceived as one that would focus on assessing the effectiveness of emotion-focused therapeutic approaches. A lack of accrual, perhaps due to low levels of patient or practitioner acceptability, led to the inclusion of an interview study that aimed to assess psychosocial aspects of the illness experience. Thus, within Study 4 provision to assess patient acceptability of an intervention focused on the expression of emotion was included. A detailed account of changes made to the research protocol along with information pertaining to ethics approval is provided in Appendix A.

All studies reported in this thesis received full ethics approval. Patients were required to provide informed consent prior to participating in the research. Copies of the Information Sheets and Informed Consent are provided in Appendices B (Cancer sample) and C (IBS sample).

1.4.1 Cancer Sample

Information sheets in the form of brochures were distributed to oncologists and waiting areas in the hospitals where ethics approval was gained. This included 3 major public hospitals in South Australia. In addition, publicity was generated via the University of Adelaide's marketing department. This resulted in the placement of editorials in one national paper (The Australian) and one local paper (The Sunday Mail in Adelaide, South Australia). Several radio stations also advertised the study; two stations interstate and two stations locally. One referral was received via the information brochure, whereas a larger number (n=46) of referrals were received via the publicity generated. All potential participants were invited to attend a screening interview to assess their suitability for participation.

The screening interview sought to establish whether potential participants met the following selection and exclusion criteria. Selection criteria specified that participants must:

- Be aged 18-74 years;
- Have received a diagnosis of cancer;
- Speak fluent English;
- Have no apparent intellectual impairment;
- Reside within the Adelaide metropolitan area; and
- Be able to attend psychological treatment on a weekly basis (for 1 hour) over an 8-week period.

Exclusion criteria specified that patients must not:

- Have a concurrent DSM-IV-TR (APA, 2000) psychotic disorder;
- Be physically unwell at the time of testing and/or are physically unable to attend trial;
- Have participated in a previous emotion-focused psychotherapy trial.

A total of 21 patients met the criteria and agreed to participate, however, one patient asked to be withdrawn from the study, leaving a cancer sample comprised of 20 participants (13 female and 7 male) ranging in age from 44 to 73 (Mean Age = 58.35, *SD* = 8.20). The reason given for withdrawal was that the participant's general practitioner had informed the patient that he did not want his patient involved in research that he was not directly involved in.

Reasons for non-participation included: located outside of metropolitan Adelaide (*N* = 7), too busy (*N* = 5), bed-ridden (*N* = 1) spoke with oncologist and advised not to participate because the patient was involved with a pharmacological trial (*N* = 1). The researcher was also unable to make contact with several potential participants referred via the publicity generated for the following reasons: moved and mail returned, did not return repeat phone calls (*N* = 11).

At the commencement of this research, the majority of patients were in remission (16/21)².

The average time since 'first' diagnosis varied substantially among participants and many of

² As described in Chapter 2 of this thesis, not all patients had been informed that they were in remission. Nevertheless, patients were described as being in remission if their last appointment with their oncologist

the participants may be better described as ‘persons who once had cancer’. Nevertheless, to be consistent with terms used in ethics applications, research protocols and information sheets provided to participants, the term ‘cancer patients’ is used throughout the thesis. For example, recruitment materials specified that the research was focused on cancer patients. Participants in responding to these materials, despite for some having received their initial diagnosis many years ago, appear to have categorised themselves as ‘cancer patients’.

1.4.2 IBS Sample

IBS patients were recruited using principles known as purposive sampling and maximum variation (Coyne, 1997, Giacomini & Cook, 2000). The aim of purposive sampling is to concentrate, in depth, on a relatively small sample (Patton, 1990). Such an approach aims to obtain ‘information rich’ cases (Coyne, 1997). Maximum variation sampling involves an attempt by researchers to ensure that participants selected will provide the best representation of the issue(s) under study (Giacomini & Cook, 2000).

Potential participants were selected purposively by the referring gastroenterologist (i.e. either a consultant gastroenterologist working in an outpatient clinic or a private consultant) keeping in mind the requirement to have representation of patients according to following criteria:

- a) Different levels of reported symptom severity (ranging between minimal to severe)
- b) Different numbers of prior consultations recorded
- c) Different education levels (did not complete high school certificate, completed high school/degree/diploma)
- d) Employed and unemployed
- e) With known psychopathology (e.g. high levels of anxiety or depression)
- f) Without known psychopathology

occurred more than 6 months ago and if they were no longer receiving treatment, and there was no further treatment planned.

- g) IBS as sole chronic condition
- h) Presence of other chronic conditions
- i) Various age levels (i.e., under 20, 20s, 30s, 40s, 50s, 60s, over 70).
- j) Representation of both males and females

Recruitment continued until 'saturation' was reached: Saturation is the point when continuing to gather information from participants is yielding no further new information (Giacomini & Cook, 2000). Nineteen patients were referred via a gastroenterologist working in an outpatient clinic and 2 patients were referred by a gastroenterologist working in private practice. The 21 participants ranged in age from 19 to 71 years with a Mean Age of 44.23 (*SD*, 15.18). There were 17 females and 4 males.

1.4.3 Conclusion

This thesis aims to work towards the development of effective strategies to manage chronic illness. A broad range of psychosocial factors are studied and includes an emphasis on understanding the nature and extent of disability in the two chronic illnesses described. Although the main emphasis when developing recommendations is on the two chronic illnesses studied, it was anticipated that knowledge developed in this thesis could also be generalised to other chronic illnesses. For example, with a particular focus on patients' experiences of illness, it was anticipated that knowledge relevant to assessing the relevance, applicability, and acceptability of public policy recommendations featured in chronic disease models (i.e. participation in decision making, shared care, and holistic care models) would emerge. In addition to providing specific knowledge concerning the role of psychosocial factors in the experience of chronic illness, a broader aim of this thesis was to critique the validity of particular research constructs used in cancer samples (e.g., inhibition, expression, fighting spirit, psychological distress), and more widely when evaluating the effectiveness of medical interventions (patient satisfaction, health care use, patient expectations and quality of life). To facilitate the development of this knowledge, a breadth of literature is consulted

and an indepth analysis of the validity of particular research constructs (e.g., inhibition, repression, fighting spirit) was incorporated and discussed in detail in Chapter 5. Given the historical emphasis of these constructs with respect to understanding how patients adjust to and cope with cancer, such a conceptual analysis was deemed essential, particularly in terms of extending the findings reported on in this thesis and when proposing future research agendas.

2 MEASUREMENT OF DISABILITY IN TWO CHRONIC ILLNESS SAMPLES: A FOCUS ON QUALITY OF LIFE AND PSYCHOLOGICAL DISTRESS

2.1 Overview: Cancer and Estimates of Disease Burden

2.1.1 Disease Burden

According to the WHO (2005), and when using the disability-adjusted-life-years measure (i.e. DALYs), cancer (5%), cardiovascular disease (10%) and chronic respiratory diseases (4%) are among the major contributors to disease burden worldwide. In Australia, in 1996, the overall burden of disease for cancer, incorporating communicable diseases, was estimated at 19% for cancer and 20% for cardiovascular diseases (Mathers, Vos & Stevenson 1999). Recent data (i.e. for 2003) shows that cancer (19%) accounted for more disease burden (i.e. as measured by DALYs) than cardiovascular disease (18%). Lung, colorectal, breast and prostate make up 50% of the total disease burden attributed to cancer (AIHW, 2006).

2.1.2 Other Indices of Disease Burden (YLL, YLD)

In addition to DALYS, other measures are used to estimate levels of disease burden. For instance, years-lost-due-to-disability (YLL) measures the number of years lost due to premature death. Years-lived-with-disability (YLD) is similar to the DALY in that it provides an estimate of the number of 'healthy' years lost as a result of disability. In 2003, estimated years-lost-due-to-disability (YLD) totalled 87,463 years for cancer (AIHW, 2006). Cancer was the 7th highest contributor to disease burden as measured by YLD, behind musculoskeletal disorders, cardiovascular disease, diabetes, chronic respiratory disease, neurological and sense disorders and mental disorders. In contrast, cancer was the leading cause of YLL (411,953) just ahead of cardiovascular disease (369,365) (AIHW, 2006).

2.1.3 Disease Burden Occurring as a Result of Cancer may be Under Estimated

There are several reasons why epidemiological measures of disease burden potentially underestimate levels of disability experienced by cancer patients.

(1) Definitions focus on physical limitations and are limited in duration

Measures of burden such as the DALY and YLD are based on definitions of ‘disability’ whereby physical and/or mobility limitations are emphasised (AIHW, 2006). Research suggests that for cancer patients, even when prognosis is excellent and physical limitations are minimal, individuals experience significant disability, particularly of a psychological nature. For instance, up to 50% of cancer patients experience psychological disorders, including acute stress disorder (ASD), post-traumatic-stress-disorder (PTSD) (Classen et al. 2001; Cordova et al., 1995), and mood disorders (Pascoe, Edelman & Kidman, 2000).

Moreover, the time-frame adopted by epidemiologists when estimating the period of disability is limited to the acute phase of the illness. According to a report published by the AIHW (1999) and when estimating figures for diseases and injuries for the 1996 period the following assumption was stated: “Those who are cured of the cancer were assumed to have negligible disability after an initial treatment and remission period” (AIHW, 1999, p. 42). This assumption contrasts with research conducted with cancer survivors that indicates that the impact of cancer can continue for many years post remission (Wenzel, DeAlba, Habbal, Kluhsman, Fairclough, Krebs et al., 2005). For instance, many patients experience changes in moods and remain apprehensive living with the fear of the cancer recurring for many years post the acute stage of the illness (Deimling, Kahana, Bowman & Schaeffer, 2002).

(2) Predictive validity of weights

Furthermore, when estimating disease burden using all indices (i.e. DALY, YLL, YLD), calculations rely on weights specified in previous epidemiological research (i.e. the Global Burden of Disease project, see Stouthard, Essink-Bot, Bonsel, Barendregt, Kramer, van de

Water et al. 1997). Although the use of standard weights provides consistency in terms of providing reliable world-wide comparisons of disease burden, no known study has assessed the predictive validity of the weights. Instead, the weights were developed by small groups of health professionals in the Netherlands who were described as ‘experts’ (Mathers, Vos & Stevenson, 1999). Using rating scales and other methods such as the person-trade off method, individuals were given hypothetical scenarios and were asked to assign weights according to their personal judgements concerning what represented ‘good health’ (Murray and Lopez, 1996).

Whilst this method does appear to ascribe a realistic weight to the severity of a condition, particularly in terms of how life threatening the condition is, it is not clear to what extent the weights provide a valid or reliable indicator of the extent of disability experienced. For instance, the value judgments made concerning what is ‘good health’ appear to favour those conditions for which death is more likely and therefore do not appear to capture domains of disability relevant to defining good health. For instance, the definition of health endorsed by the WHO (1946, p. 100) “defines health as a state of complete physical, mental, and social wellbeing, not merely the absence of disease or infirmity”.

(3) Co-morbidity estimates between mental and physical health inadequate

Health organisations have begun to report the impact of some non-fatal conditions, in particular, mental disorders on disease burden. Whilst these estimates factor in co-morbidity within categories of mental disorders, no provision is made for the presence of co-morbidities that occur between physical and mental conditions (AIHW, 2006).³

³ In a 2007 report, improvements in methodology have occurred and some consideration is given to the extent of co-morbidity between some physical and mental disorders. For instance, it is recognized that anxiety and depression are prospectively linked with ischemic heart attack and suicide, thus disease burden estimates provided specify the increased level of disease burden for the combined category (i.e. from 7.3% to 8.2%) (Begg, Vos, Barker, Stevenson, Stanley & Lopez, 2007).

According to Prince et al., (2007, p. 860)

... the interaction between mental disorder and disability is more complex and extensive than the WHO report suggests. Depression predicts the onset and progression of both physical and social disability. Conversely, disability is an important prospective risk factor for depression ...

Prince et al. (2007) argue that the complexity of the relationships among mental disorders and physical illness are unlikely to be captured in current epidemiological measures. For instance, they review a range of studies that provide evidence for a link between pre-existing mental disorder (i.e. depression, anxiety) and the subsequent development of physical disease. This finding appears to be applicable across a range of physical illnesses including non-communicable diseases such as cardiovascular disease and diabetes and communicable diseases such as tuberculosis and malaria. With reference to non-communicable diseases, their review of research found a prospective link between depression in 15/22 studies reviewed and anxiety in 4/8 studies reviewed.

Furthermore, the impact of mental disorders on physical illness is complex as mental disorder can also occur following the diagnosis, and/or the treatment associated with a particular illness. For instance, the presence of depression is shown to increase following myocardial infarction and is associated with a poorer prognosis (Prince et al., 2007). Mental disorders are frequently reported to occur as a result of a diagnosis of cancer (Classen et al., 2001; Pascoe et al., 2000), although, depression has also been linked with the development of cancer. Spiegel and Giese-Davis (2003) review studies that attempt to demonstrate a link between depression and an increased incidence of cancer. For instance, 2,020 randomly selected middle aged men who were assessed to have depression in 1957-1958, were at follow-up (17 years later), more likely to have died from cancer. Using cases where the severity of the depression was taken into account, a significant and prospective relationship between

depression and cancer incidence was evident (see Shekelle, Raynor, Ostfeld, Garron, Bieliauskas, Liu et al., 1981).

2.2 Irritable Bowel Syndrome: Estimates of Disease Burden

2.2.1 A Lack of Disease Burden Data

Specific epidemiological data relevant to IBS in Australia could not be located. IBS has been described as a somatoform disorder, yet, in contrast with other somatoform disorders (e.g., chronic fatigue syndrome) national disease burden data do not provide information concerning the impact of IBS. For example, chronic fatigue syndrome is included along with sudden infant death in disease burden data under a category: Ill-defined conditions. Indeed, as is evidenced in the following extract from a government report of disease burden in Australia, figures cited by health organisations do not claim to be representative of all chronic illnesses:

The chronic diseases are too many, and too difficult to classify, for all of them to be covered in this report. Instead, a selection of the most important – those causing much of Australia’s disease burden is profiled here. Several of the chronic diseases included in this section are accorded the status of National Health Priority Area by Australian health ministers. This is on the basis of their health impact, the potential to reduce their burden, and community concern about them. Cardiovascular disease, cancer, diabetes, asthma, and arthritis and musculoskeletal conditions fall into this category.

AIHW 2006, p.80

Other sources of potential data included the National Health Survey conducted in 1995, 2001 and 2004-2005 and the South Australian Health Omnibus Survey (Wilson, Wakefield & Taylor, 1992) which has collected data from 1990 to present. According to the National Health Survey 2004-2005 report, the main chronic illnesses identified by Australians include: long/short sightedness, back-pain, hay-fever, allergic rhinitis, deafness, hypertension, asthma, chronic sinusitis, asthma, migraine, and osteoarthritis. Similarly, the Health Omnibus Survey

only includes data relevant to the National Health Priority Areas (NHPA). The NHPAs focus on arthritis and musculoskeletal disorders, asthma, cancer, cardiovascular disease, diabetes, injury and mental health (AIHW, 2006).

2.2.2 Somatoform Disorders

In Australia, limited data were available concerning the prevalence and the costs incurred as a result of somatoform disorders. The only data found were included in a National Health Survey report (AIHW, 2007). For example, 10% of separations in public and private hospitals throughout Australia were as a result of conditions whereby a principle diagnosis of neurotic, stress-related and/or somatoform disorders was made. In the reporting period of 2003 to 2004 a total of 315,000 (9.5% of total) contacts were made in government operated community mental health services as a result of neurotic, stress-related and/or somatoform disorders (AIHW, 2007).

2.2.3 Economic Burden and Health Care Expenditure

Other indicators of burden such as economic burden occurring due to absenteeism (i.e. losses of productivity) and/or health expenditure could provide an indicator of the extent of impact of IBS. Again, data were unavailable in Australia. Nevertheless, data reported abroad provides some indication of the extent of disability reported in relation to IBS. IBS patients account for 3.5 million visits annually to general practitioners in the United States (Martin, Barron & Zacker, 2001). In the United States, costs are estimated to be in the order of US \$12,000 per annum per patient (Jones, Crowell, Olden & Creed, 2007). Total expenditure, per year, is estimated at 1.6 million dollars in direct costs with a further 19.2 billion in indirect costs (Sandler, Everhart, Donowitz, 2002). Indirect costs are linked with reductions in productivity due to high levels of absenteeism (Dean, et al., 2005). Other indicators of total burden incurred as a result of IBS come from figures from the UK and US which indicate that patients with IBS account for approximately 12% of consultations in primary care, and up to an estimated 50% of consultations in tertiary care and clinical practice (Jones et al. 2007).

2.2.4 Other Indicators of Disability

According to Blanchard, Scharff, Schwarz, Suls and Barlow (1990), 50% to 90% of IBS patients who seek medical treatment have diagnosable psychopathologies such as anxiety, depression, and/or personality disorders. Studies show that patients who seek treatment in outpatient clinics have higher levels of depression and anxiety than the general population (Schwarz, Blanchard, Berreman, Scharff, Taylor, Green et al., 1993). There also appears to be a higher incidence of early abuse and personality disorder in IBS patients than in patients with organic gastrointestinal disorders (Blanchard, Keefer, Lackner, Galovski, Krasner & Sykes, 2004; Drossman, Leserman, Nachman, Li, Gluck, Toomey, & Mitchell, 1990).

2.2.5 The Issue of Comorbidity in IBS?

Understanding the relationship between illness and co-morbidity with psychological disorders and IBS is awkward. For instance, technically, in the absence of a known physical cause, the disorder is defined as essentially a psychological disorder (i.e. a somatoform disorder). Thus, the issue of psychological co-morbidity does not apply. Drossman's (1998) conceptual model of functional gastrointestinal disorders incorporates psychological conditions (stress and anxiety) in the genesis of IBS. The model draws in principle from Engel's (1971) bio-psychosocial explanation of illness whereby disease (i.e. where known pathophysiology can be identified as measured via x-ray, blood tests, endoscopy) is distinguished from illness. Illness is defined "... as the patient's perception of ill health, which is evident from the person's symptom reports, perceptions, and behaviour" (Drossman, 1998, p. 258).

2.2.6 Drossman's (1998) Conceptual Model of IBS

As shown in Figure 1, psychosocial factors play a central role in the development and experience of illness. According to Drossman (1998), stress may be implicated in early life experiences, as per environmental factors such as sexual abuse. Second, psychosocial stress can include life stress (i.e. stressful events) and psychological distress (anxiety). Levels of social support and or coping strategies may also interact or mediate the effects of stress. For

instance, patients who have the tendency to catastrophise tend to report more severe symptoms (Lackner, Quigley and Blanchard, 2004).

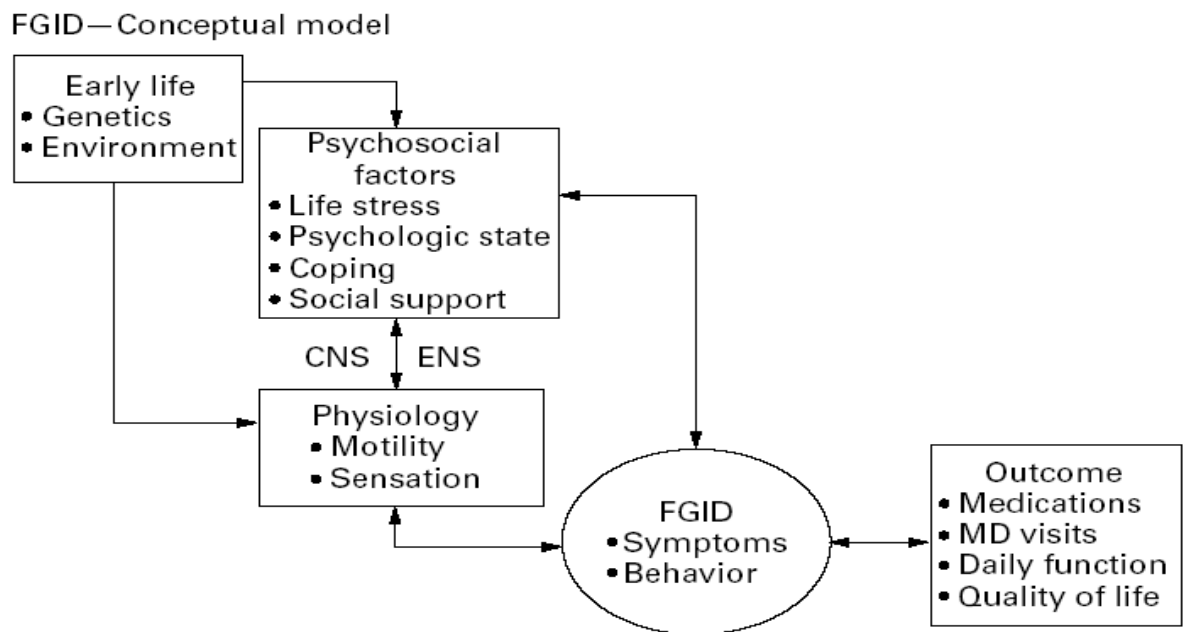


FIGURE 1: IBS Conceptual Model

Drossman, Creed, Olden, Svedlund, Toner & Whitehead (1999)

Source: Gut (1999), p. II26

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These factors, as depicted in Figure 1, when combined may eventually lead to the development of symptoms. Then, as shown in the model, once the individual experiences the illness, they are more likely to access medical services, and report impairments in daily functioning and quality of life. Importantly, in this conceptual model, Drossman et al. (1999) propose the mechanism by which these factors impact on physiology (e.g., the CNS-ANS connection). Drossman et al. (1999) cite a range of physiological studies in support of the central and autonomic nervous system connection, particularly with respect to evidence of the role of the CNS in modulating gut motility. For instance, studies using positron emission

tomography (PET) demonstrated dysregulated motility and altered rectal distension in IBS patients. Other case studies, using functional magnetic resonance imaging (fMRI), show that the midcingulate cortex (MCC) is over activated in patients with extreme psychosocial distress (i.e. defined as high levels of stressful incidents). Resolution of psychosocial impairment was shown to reduce activation of the MCC (Drossman, Ringel, Vogt, Leserman, Lin, Smith & Whitehead, 2002).

2.4 Quality of Life – A Measure of Total Disability

Disease burden data emphasises those conditions for which a disease state can be identified in contrast to conditions for which there is no known organic disorder. A definition of ‘illness’ may be more useful than the absence of disease particularly when attempting to explain the development of conditions such as IBS. Even in conditions for which a disease state can be identified, epidemiological measures are limited in the extent to which they measure total disability. For cancer, epidemiological measures are limited to the acute stage of the illness and tend to emphasise disability occurring as a result of physical limitations. In contrast, and as reviewed subsequently, measures of quality of life aim to assess total disease burden, incorporating a broad approach to defining disability.

Mozaffari et al. (2007, p. 261) offer the following definition of Quality of Life (QOL):

It is defined as the subjective perception of the impact of health status, including disease and treatment, on physical, psychological, and social functioning and well-being.

Importantly, definitions and measures used to assess QOL are consistent with holistic definitions of health as per the WHO (1946) definition that conceives of ‘health’ as relating to physical, mental and social domains. However, the definition provided by Mozaffari’s (2007) focuses on ‘disease’ and thus appears more consistent with biomedical model views of disease, and not ‘illness’ as is conceived within bio-psychosocial models such as those proposed by (Engel, 1977). Nevertheless, Osoba (1991) in discussing the utility of quality of

life measures suggests that they provide a measure of total disease burden occurring as a result of the disease and treatment. Thus, disease burden is conceived in terms of patients' perceptions of the impact of disease and not necessarily the disease itself. Thus the approach, with its emphasis on a patient's perception of disability, is consistent with bio-psychosocial accounts such as is evident in Engel's (1977) bio-psychosocial model and Drossman's (1998) conceptual model of IBS.

2.4.1 Increasing Use of QOL Measures

Some researchers suggest that an increasing interest in the inclusion of quality of life measures both in clinical practice and research can be attributed to the changing nature of disease from acute to chronic, and from incurable to curable (Mozaffari, et al., 2007). Over the past decade the rate of inclusion of quality of life measures in oncology trials has increased from 26% (in the late 1980s) to 74% (Cella, 2005). A search on PUBMED using the terms 'quality of life and cancer' identified 23,673 articles. In contrast and when using the search terms "quality of life and Irritable Bowel Syndrome", just 384 articles were identified. Of these articles many used the term 'quality of life', although they did not specifically measure quality of life using a validated instrument. Similarly, using MedLine from Science Direct, 3730 cancer articles were found compared with 87 IBS articles. Using PsychInfo, 2,124 articles were identified, compared with 50 for IBS.

2.4.2 Previous Research: Quality of Life in Cancer Populations

In cancer populations, impaired quality of life is frequently reported (Brucker, Yost, Cashy, Webster, Cella, 2005; Sprangers, Taal, Aaronson, le Verde, 1995; Ward, Hahn, Mo, Hernandez, Tulsy & Cella, 1999; Wenzel, Huang, Monk, Rose & Cella, 2005) with reduced quality of life evident in long term survivors (Mols, Coebergh, Vande Poll-Franse, 2007; Rao, Demark, Wahnefried, 2006; Wenzel et al., 2002). These impairments appear to occur independently of time since diagnosis, treatment modality and stage of disease (Bradley, Rose, Lutgendorf, Costanzo & Anderson, 2007), although some studies suggest that quality of

life is improved after 10 to 15 years following diagnosis than after 5 to 9 years (Mols et al., 2007).

The impairments are observed across a range of different types of cancers, including but not limited to: breast (Bottomley & Therasse, 2002), testicular (Wiechno, Demkow, Kubiak, Sadowska, Kiminska, 2007), prostate (Tomicich, 2007) cervical (Wenzel et al., 2005), Hodgkin's Lymphoma (Absolom, Greenfield, Ross, Davies, 2007), endometrial (Bradley et al., 2007), and lung (Montazeri, Gillis & McEwen, 1998).

Impairments in quality of life occur independently of gender, although quality of life appears to decline with age (Brucker et al., 2005). Observed impairments are not always significant when compared with normative samples that comprise individuals living with chronic illness (Brucker et al., 2005). Furthermore, the impediments observed are not always observed across all domains relevant to health. For instance, Cella, Hahn and Dineen (2002) report that cancer patients (mixed diagnosis) had comparable levels of quality of life in the physical, functional, and emotional domains as a 'healthy' US population but were impaired in the social well-being domain. Moreover, across a range of studies negative correlations were shown between measures of distress and quality of life (Johnson, Pideran, Sloan, Huschka, Atherton, Hanson et al. 2007; Ward et al., 1999). Thus, quality of life measures may also capture the impact of emotional states such as anxiety and depression.

In some terminally ill cancer samples, quality of life is higher than would be expected and some commentators suggest that a belief or involvement in religion and/or spirituality might be responsible for this finding (Brady, Peterman, Fitchett, Mo, & Cella, 1999). Indeed, Brady et al. (1999) report a correlation between spiritual well-being and overall quality of life ($r = .58$, $p < .01$). Nelson, Rosenfeld, Breitbart and Galietta (2002) report a negative correlation between depression and the meaning/peace subscale of the spiritual wellbeing scale ($r = -.51$,

$p < .01$). According to Daugherty, Fitchett, Murphy, Peterman, Anik, Hlubock and Tartaro (2005) between 65 and 90% of cancer patients report benefits of religion including, providing hope, increased social support, and finding meaning in one's illness.

Inclusion of quality of life measures is not without its critics and some question the lack of demonstrable links with improved patient outcomes; a lack of conceptual model or theoretical development that explains the relationship between symptoms and decrements in quality of life (see editorial by Cella, 2005). Advocates for using quality of life measures emphasise their clinical utility in terms of facilitating improved patient-practitioner communication, identifying problems and establishing priorities (Kobayashi, Green, Shimonagayoshi, Kanemoto, Dasai, Itoh, et al. 2005).

Advocates for using quality of life measures view illness as encompassing many aspects of a patient's life, not just the physical domain. According to Brady et al. (1999) advocates for including the spiritual dimension as an additional domain in quality of life measures are essentially proposing a bio-psychosocial-spiritual model (Hiatt, 1986).

Brady et al. (1999, p. 425) note the importance of including spirituality in quality of life measures:

If spirituality is indeed a factor that enables a person to derive deep satisfaction from life despite symptom load, and we fail to measure it, we are in danger of miscalculating the actual perceived 'burden' of the disease, and perhaps severely underestimating the true 'quality' of a person's life. We may also be at a loss to explain why one patient with high pain is reporting greatly diminished QOL, while another with the same level of pain is still reporting high levels of life enjoyment and satisfaction.

Brady et al. 1999, p. 425

2.4.3 Previous Research: IBS and Quality of Life

Compared with research in the cancer area, fewer QOL studies exist. Nevertheless, an IBS specific quality of life measure was developed (Wong, Guyatt, Cook, Griffith & Irvine, 1998), although the validity of the measure is questionable. For example, the items were derived from a small number of interviews (e.g., 5 patients and 5 health care providers). Luscombe (2000) in reviewing quality of life studies that used a standardised QOL measure, concludes that IBS patients report poorer quality of life as compared with US norms and that quality of life is correlated with symptom severity and health care use.

Other researchers also report that IBS patients have impaired quality of life as compared with normative populations in France (Amouretti, Le Pen & Gaudin, Bommalaer, Frexinos, Rusniewski et al., 2006). Furthermore, IBS patients rate their quality of life as significantly poorer than do patients with other chronic conditions such as panic disorder, rheumatoid arthritis, migraine and asthma (Frank, Kleinman, Rentz, Ciesla, Kim & Zacker, 2002). Patients with IBS and Irritable Bowel Disease (IBD) report similar impairments on quality of life measures (Pace, Molteni, Bollani, Sarzi-Puttini, Stockbrugger, Bianchi-Porro et al., 2003). In IBD (i.e. ulcerative colitis and Crohn's disease), patients experience similar symptoms to IBS patients but the physical origin of the illness is known (Loftus, 2004).

2.5 Summary and Aims

Significant health care expenditure and individual disability occur as a result of individuals living with a chronic illness. The extent of impact of non-fatal conditions, particularly those with a non-organic cause (i.e. IBS) remains unclear. Furthermore, for life-threatening conditions, such as cancer, health care expenditure and disease burden estimates tend to reflect costs and disability incurred during acute phases of the illness (AIHW, 1999; AIHW, 2006; AIHW 2007) and emphasise physical limitations.

Current epidemiological measures do not appear to be designed to assess disability with the kind of specificity required to provide holistic estimates of patients' perceptions of disability. In contrast, quality of life measures define 'health' in broader terms and incorporate a more holistic view of illness, incorporating, physical, mental, social and spiritual domains. A conceptualisation that incorporates a holistic view of illness, as opposed to a focus on the absence of disease, appears to be particularly relevant when assessing disability in the IBS population.

Thus, in this study the major aim was to provide descriptive data relevant to describing perceived levels of disability experienced in the two chronic illness groups reviewed. Disability was measured using a validated quality of life measure and a measure of distress. Distress in this study is defined as incorporating chronic states of stress, anxiety and depression. To facilitate an understanding of the extent of disability observed in these two chronic illness groups, available normative data and data reported in studies focusing on a range of chronic illnesses were included. When data were available, effect sizes were calculated to provide an indication of the extent of difference between groups. Data relevant to demographics, medical information, and health behaviours are also presented in the Results section of this chapter.

2.5.1 Hypotheses

No known study has explicitly compared levels of distress and quality of life between conditions for which there is a known organic cause (cancer) with one where there is no known organic cause (IBS). Thus, specific hypotheses concerning the extent of differences between these groups are not proposed. Nevertheless, comparisons between each of the chronic illnesses studied and with other chronic illnesses will be presented. On the basis of the literature reviewed, the following hypotheses are proposed.

1. The cancer group will report lower scores on the quality of life measure (indicative of impairment) as compared with data representative of a healthy population.
2. The IBS group will report lower scores on the quality of life measure as compared with data representative of a healthy population.
3. The cancer group will report higher scores on each of the distress measures (indicative of increased distress) as compared with general populations.
4. The IBS group will report higher scores on each of the distress measures as compared with general populations.
5. In both groups, scores on the distress measures will be negatively associated with scores on the quality of life measure.

2.6 Method

2.6.1 Participants

As reviewed in Chapter 1, the total chronic illness sample (i.e. cancer and IBS participants) comprised 41 participants. The response rate achieved for the questionnaire was 80% for the cancer sample and 61.9% for the IBS sample. Thus, the cancer sample comprised 16 participants: 11 females (Mean age = 55.27, *SD* = 8.69) and 5 males (Mean age = 59.40, *SD* = 9.65). The responders for the IBS sample comprised 13 participants, all of whom were female. They ranged in age from 20 to 71 (Mean age = 44.46, *SD*=16.26). Thus, a difference between responders and non-responders in the IBS sample was gender as no males from the IBS total sample returned the questionnaire. This pattern was not observed in the cancer group, with a similar proportion of females (11/13) versus males (5/7) returning the questionnaire.

2.6.2 Measures

The questionnaire contained a range of standardised psychological measures with additional questions added to assess for demographics (e.g., gender, occupation, living arrangements,

age, ethnicity and religious/spiritual beliefs) and health behaviours (e.g., exercise, alcohol consumption and smoking).

Demographics

Three single items assessed for descriptive statistics with respect to date of birth, gender, and country of birth. A further three items assessed for categorical data with respect to living arrangements, occupation and education level achieved. Response alternatives for living arrangements included 'live on own', 'with family', 'with partner', 'in shared accommodation', or 'other'. For occupation, response alternatives included: 'not working', 'home duties', 'clerical/secretarial', 'sales', 'tradesperson', 'manager/professional', and 'other'. And, for education level achieved response alternatives included 'primary', 'secondary', 'technical and further education (tafe)', 'tertiary', 'undergraduate', or 'post-graduate'.

Religious/spiritual beliefs

Two items were included to assess for Religious/Spiritual beliefs. For example, the first item was worded: "Do you practice, or are you a member of a particular religion or spiritual faith? Responses included 'no' (scored 1) and 'yes' (scored 2). A second item followed: "If yes, on a scale of 1 to 5, how would you describe your involvement with this religion/faith?" Responses were scored on an ordinal scale from: 1 = very little involvement, to 5 = very strongly involved.

Health behaviours: exercise, alcohol consumption, smoking

Items that assessed for health behaviours such as exercise, alcohol consumption and smoking were derived from standardized measures. The International Physical Activity Questionnaire (Version 2, 2004; www.ipaq.ki.se) includes six items that assess the 'frequency' in days and 'duration' in minutes of exercise according to 3 dimensions: (1) 'vigorous exercise' (defined

as "... activities like heavy lifting, digging, aerobics or fast bicycling"); (2) 'moderate exercise' (defined "... as activities like carrying light loads, bicycling at a regular pace, or doubles tennis") and; (3) 'walking' (defined as "... no less than 10 minutes of walking"). Participants were asked to indicate the number of 'days per week', or the 'hours per day', or 'minutes per day' for each exercise dimension. 'No exercise', or don't know, were also provided as responses.

To score for a categorical variable that includes 3 levels ('Inactive', 'Minimally Inactive', and 'High Active) computation of the total score requires summation of the 'duration' and 'frequency' of all physical activity dimensions (i.e., walking, moderate intensity and vigorous intensity).

The Alcohol Use Disorders Identification Test (AUDIT, 2nd Edition) was developed by the World Health Organisation (Babor, Biddle-Higgins, Saunders & Monteiro, 2001) and is currently the most widely acknowledged tool for the assessment of alcohol consumption. The total AUDIT comprises 10 items that assess for 'Alcohol Consumption', 'Alcohol Dependence' and 'Hazardous Alcohol Use'. Only items reflective of 'Alcohol Consumption' (i.e., 'frequency', 'amount', 'extent of consumption – binge drinking') were included. High scores on these items, in the absence of positive scores on other omitted items (i.e., 'Alcohol Dependence' and 'Hazardous Alcohol Use') provide an indication of potential hazardous alcohol use.

The frequency of alcohol consumption was assessed with the following question: "How often do you have a drink containing alcohol?" Scoring of response alternatives occurred on a Likert scale as follows: never (0), monthly or less (1), 2 to 4 times a month (2), 2 to 3 times a week (3), 4 or more times a week (4). The Typical Quantity consumed was assessed by the statement: "How many drinks containing alcohol do you have on a typical day when you are

drinking?” Response alternatives included 1 or 2 (0); 3 or 4 (1); 5 or 6 (2); 7 to 9 (3); or, 10 or more (4). The extent of excessive consumption, or ‘binge drinking’ was assessed by the statement: “How often do you have six or more drinks on one occasion?” Response options included, never (0), less than monthly (1), monthly (2), weekly (3), daily or almost daily (4).

In 1997, the Australian Institute of Health and Welfare (AIHW) introduced a set of national standard questions and recommended their use in all population assessments of smoking behaviour (Mullins, Hill & Borland, 2000) Two items assess for the ‘frequency’ and ‘amount’ of smoking of cigarettes or other tobacco related products; and a further two items enable the creation of a categorical variable reflective of smoking status (i.e., ‘non smokers’ or ‘ex smokers’) The first item assesses current smoking status with the following statement: “Do you currently smoke cigarettes, cigars, pipes, or any other tobacco products?” A further statement asks ‘current smokers’ to specify according to the frequency of use (i.e., daily; at least weekly (not daily); less often than weekly; or not at all). A second item assesses for the amount of cigarettes smoked on a weekly, or daily basis. Items that discriminate among non smokers and ex-smoker are reflected in two statements including: “In the past have you ever been a daily smoker? (yes, no), and “over your lifetime would you have smoked at least 100 cigarettes or a similar amount of tobacco?”

Other substances/medicine and vitamin use

One item, “Do you take any other substances?” assessed for the use of illegal substances. If participants responded ‘yes’, then they were asked to indicate “How much?” and “How often?” with reference to a list of substances such as marijuana, cocaine, speed, ecstasy/amphetamines, opioids, hallucinogens, or other. Two items assessed for the amount and frequency of medicine and vitamin use.

Quality of life

The Functional Assessment of Chronic Illness Therapy (FACIT; Cella, 1997) is a comprehensive measurement system designed to measure the impact of chronic illness on quality of life. The core questionnaire, referred to as the FACT-G comprises 27 items. The measure was initially developed from interviews involving 135 cancer patients and 15 oncology specialists. Reportedly, the measure has been used to assess quality of life in patients with other chronic illnesses such as multiple sclerosis, HIV and Parkinson's disease (Lent, Hahn, Eremenco, Webster & Cella, 1999). The instrument is highly regarded as a psychometrically valid instrument to measure quality of life (Daugherty et al., 2005).

The measure provides an assessment of an individual's well being according to 4 dimensions: Physical well-being, social/family well-being, emotional well-being, functional well-being. Physical well-being was assessed by 7 items such as "I have a lack of energy"; "I have pain; "I am bothered by the side effects of treatment". Social and Family Well-being was assessed by 7 items such as "I feel close to my friends"; and, "I feel close to my partner (or the person who is my main support)". Emotional well-being was assessed by 6 items that include statements such as: "I feel sad" and "I am losing hope in the fight against my illness". Functional well-being was measured by 7 items with statements such as: "I am able to work (at home or work)"; "I am able to enjoy life"; and, "I am sleeping well". All items were scored on a 5 point scale from 0 = "not at all" to 4 = "very much". As per the instructions provided in the manual, several items were reverse coded.

The US population forms the basis of the normative data for healthy groups and cancer groups. The general population comprises 1,400 adults who were randomly drawn from 100,000 individuals participating in an Internet based survey panel. The cancer sample comprises of 2,236 participants with a variety of diagnoses. The criterion used for selection

was that the patients must have received a diagnosis at least 2 months ago and have at least 3 months to live (Brucker et al., 2005).

Guidelines with respect to the FACT- G enable an estimation of statistical significance (i.e. effect size) (Brucker et al., 2005) and clinical significance (i.e. ‘meaningful’ difference). For example, 197 participants completed the FACT-G alongside a measure of global change (Cella, Eton, Lai, Peterman, & Merkel, 2002). Participants were required to indicate on a rating scale the extent to which their quality of life had worsened, improved, or had not changed. These ratings were then calibrated alongside the FACT-G scores to produce meaningful difference scores. As reported by Cella, Hahn et al. (2002) and Cella, Eton et al. (2002); and Webster, Cella and Yost (2003), meaningful differences for the FACT-G refer to differences in the range of 3 to 7 scores.

Spiritual wellbeing

The FACIT-SP12 is designed to be used in conjunction with the FACT-G and it provides information pertaining to a purported additional dimension of well-being, ‘spiritual well-being’. It is assessed under the “Additional Concerns” category and includes 12 items. Statements include: “I feel peaceful”, I have a reason for living” and “I find strength in my faith or spiritual beliefs”. Again, items were scored on a scale from 0 = “not at all” to 4 = “very much”. Several items were also reverse coded. Although the scale is generally used in conjunction with the FACT-G, it has also been used separately in studies. The measure comprises two subscales incorporating a meaning/peace subscale and a faith subscale. The instrument, used separately, has demonstrated reliability and validity in cancer samples and a sample of AIDS patients with Cronbach’s alpha $r = 0.87$ for the total scale, $r = 0.81$ for the meaning/peace subscale and 0.88 for the faith subscale (Brady et al., 1999, Fitchett, et al, 1996; Lin, Bauer-Wu, 2003).

Stress, anxiety, depression

The Depression, Anxiety and Stress Scale (DASS; Lovibond & Lovibond, 1995) was used to assess for levels of stress, anxiety and depression. The measure contains 42 items divided into 3 subscales. Participants were asked to indicate on a 4 point severity/frequency scale, from 0 (did not apply to me) to 3 (applied to me very much, or most of the time) the extent they had experienced symptoms over the past week. The depression scale includes items reflective of symptoms of clinical depression such as hopelessness and/or a lack of interest/involvement in activities, such as “I couldn't seem to get any enjoyment out of the things I did”. Items forming the anxiety subscale measure levels of autonomic arousal, skeletal muscle effects, situational anxiety, and subjective experience of anxiety affect. An example of an item is “I perspired noticeably (e.g., hands sweaty) in the absence of high temperatures or physical exertion”. The stress subscale is designed to measure non-specific arousal such as having difficulty relaxing, and being easily agitated and includes items such as: “I found it difficult to relax” (Lovibond & Lovibond, 1995).

2.6.3 Procedure

Following participating in an interview with the Researcher (see Chapters 6 and 9), the cancer patients and IBS patients were given a copy of a questionnaire and asked to return to the researcher in a self-addressed envelope⁴. Participants were asked to return the questionnaire within 7 days of the interview. They were contacted by telephone, and letter, if they had not returned the questionnaire. This method did not result in the return of any additional questionnaires, thus it did not improve the overall response rate.

2.7 Results

2.7.1 Demographic, Medical, and Health Behaviours: Cancer Sample

Diagnoses

⁴ The cancer participants completed a larger number of measures than the IBS patients. A copy of each of questionnaires is not provided in the Appendix. All measures were validated measures and many were subject to special permission requests and subsequent copyright restrictions.

Participants had a variety of principal diagnoses, including breast (N=3); head and or neck (N=3); non-Hodgkin's lymphoma (N=2); lymphoma (N = 1); prostate (N=1), lung (N=1), testicular (N=1); colorectal (N=2), acute myeloid leukaemia (N=1); and, stomach (N=1). At the time of completing the questionnaire, 81.25% (13/16) of participants in the cancer patient sample were in remission (13/16) and 3 participants were currently receiving treatment.⁵ Three patients had diagnoses of recurrence; 2 of these patients were currently receiving treatment and one patient with a new diagnosis was currently receiving treatment. Time since first diagnosis ranged from 6 months to 13 years (Mean months = 54.62, *SD* = 43.53).

Country of birth, living arrangements, and education

The majority of participants (i.e., 68.75%) identified their country of birth as Australia. Relatively equal representation of occupational groups (e.g., not working, sales, clerical, and professional) and education levels were observed. For example, (8/16) of the sample reported achieving a secondary level of education and (8/16) reported reaching a diploma, tertiary and/or post graduate level of education. Approximately 80% (13/16) of cancer patients lived with their family or partner.

Other chronic illnesses

Almost 70% (11/16) of patients reported being diagnosed with a range of chronic illnesses with some patients reporting several co-morbid physical and mental conditions. Physical illnesses included: cardiovascular disease, hypertension, high cholesterol, diabetes, herpes, scleroderma, osteoporosis, menopause, Raynaud's syndrome, thyroid, migraine and chronic gastritis. Mental disorders reported by participants included bipolar disorder, anxiety, and depression.

⁵ Five participants indicated that they had never been formerly advised that they were in remission and were unsure of their remission status. These participants were classified as being in remission. For instance, in each of these cases the last date of treatment was greater than 6 months and no further treatment was proposed.

Health behaviours

Two patients identified themselves as smokers, and 5 participants' scores on the AUDIT (Babor et al. 2001) indicated potential hazardous use of alcohol. For instance, 5 participants reported drinking more than 6 drinks on one occasion. Of the total group, fifty per cent of cancer participants drank regularly (2 or 3 times a week) and fifty percent of cancer participants reported never, or occasionally (i.e., monthly) drinking alcohol.

Data for responses on the IPAQ (Version 2, 2004; www.ipaq.ki.se) exercise questionnaire could not be computed due to extensive missing data on some domains assessing for levels of physical activity (i.e., vigorous, moderate, walking) or on items measuring the time spent exercising (i.e., either the days per week, or hours, or minutes spent engaging in the activity). For instance, patients tended to answer the questions concerning the level of exercise (i.e. vigorous or moderate) but then failed to provide further information on either the 'days per week' they engaged in the physical activity, or the 'amount of time' (e.g., hours or minutes) they engaged in the activity. Up to 75% of items had missing values on either of these items.

Thirteen of the 16 participants (81%) in the cancer sample were taking prescription medication and 31% (5/16) reported taking vitamins.

2.7.2 Demographic, Medical, and Health Behaviour Characteristics: IBS Sample

Diagnoses

Eight IBS patients provided a date of diagnosis; others left this question unanswered. Of those responses received, the date of diagnosis ranged from 2 months to 20 years (Mean = 50.5 *SD* = 80.82). One patient specified the date and type of diagnosis as diverticular disease, not Irritable Bowel Syndrome⁶.

⁶ The Participant's Gastroenterologist confirmed that this patient had been given a diagnosis of IBS.

Country of birth, living arrangements and education

Fifty three percent (7/13) of participants identified their country of birth as Australia, and 53% reported living with their family or a partner. Participants were employed in a range of occupations including clerical (N=3), sales (N=1), trades (N=1), manager/professional (N=1). Three participants identified themselves as performing home duties, one was unemployed and 3 'other' categories were specified; these included the occupations of teacher, cleaner, and student. One participant had achieved a primary level education. Seventy five per cent (8/13) had achieved secondary education level and 38.5% (5/13) reported achieving higher levels of education (i.e. diploma and post-graduate education).

Other chronic illnesses

Fifty three percent (7/13) reported that they had additional chronic illnesses including, hypertension, arthritis, back and hand pain, diverticular disease, menopause, arthritis and mood disorders, including bipolar and anxiety disorder.

Health behaviours

Three participants identified themselves as regular smokers, and six participants indicated hazardous alcohol use (i.e. reported drinking more than 6 alcoholic drinks on one occasion). Forty six percent (6/13) of IBS patients were regular drinkers with approximately half of these participants drinking more than 3 drinks on each occasion. Five participants identified themselves as smokers. Whilst some data were missing on the IPAQ, sufficient data to enable reporting were available.

Reported are results for which relatively complete records were available. Almost 70% (9/13) of participants reported walking 1 to 7 days per week for 30 minutes to 2 hours in duration. Forty six percent (6/13) reported that they engaged in vigorous activity at least once per week

for 1 hour to 12 hours per day⁷. Seventy six percent (10/13) reported taking prescription medicine and 30% (4/13) reported taking vitamins on a regular basis. Thirty percent of IBS patients (4/13) reported using a range of illegal substances on a regular basis.

Religion

In the cancer sample, half of the patients identified themselves as being affiliated with a religion. In terms of their involvement, 75% described their involvement as very little or slight (Mean = 1.81, *SD* = 1.37). In the IBS sample, 76.9% (10/13) of participants identified themselves with a religion. In terms of describing their involvement, 6 participants reported having very little involvement and 7 reported that they were either moderately, strongly or very strongly involved (Mean = 2.53, *SD* = 1.61).

2.7.3 FACT-G and DASS: Missing Data, Distributions and Reliability

Tables 1 and 2 provide descriptive data for the FACT-G total scores and subscale scores, along with the depression, anxiety and stress subscales for the DASS for the cancer sample and IBS samples respectively.

Missing data

Missing data were minimal for both measures and in both samples, with the exception of 1 cancer patient for whom data on the entire DASS (i.e. 42 items) were missing. Data for this participant were included for data reporting on the FACT-G and subscales, however, they were excluded in any inferential statistics requiring complete data for both the FACT-G and DASS.

⁷ Although 12 hours of exercise per day may be an error, it could also be associated with an extreme focus on one's body image/weight. This was evident in the Study reported on in Chapter 9.

TABLE 1
Cancer Sample - Descriptive Statistics for FACT-G and DASS Scales

	<i>Min</i>	<i>Max</i>	<i>Mean</i>	<i>SD</i>	<i>Skew- ness</i>	<i>Std. Error</i>	<i>Kurtosis</i>	<i>Std. Error</i>	<i>Alpha</i>
AGE	45.00	73.00	57.56	8.89	.25	.56	-1.01	1.09	
PWB	13.00	28.00	22.43	4.08	-.59	.56	.30	1.09	.73
SWB	7.00	26.00	17.37	5.18	-.14	.56	-.40	1.09	.71
EWB	11.00	23.00	19.25	2.95	-1.27	.56	3.10	1.09	.72
FWB	12.00	28.00	21.43	5.05	-.540	.56	-1.05	1.09	.85
SP12	24.33	48.00	32.20	7.07	1.11	.56	.66	1.09	.79
FACT-G	64.00	97.00	80.50	11.49	-.15	.56	-1.45	1.09	.82
Stress	.00	19.00	7.06	5.80	.89	.56	.066	1.09	.89
Anxiety	.00	20.00	4.33	5.92	1.73	.56	2.44	1.09	.88
Depression	.00	28.00	4.80	7.44	2.38	.56	6.17	1.09	.96

PWB: Physical well being; SWB: Social and family wellbeing; EWB: Emotional well being; FWB: Functional well being; SP12, Spiritual wellbeing. (N = 16 for FACT-G scales; N = 15 for DASS scales)

Fourteen individual items (from a total of 81 items) had missing data in the IBS group, and 8 items (from a total of 81 items) had missing data in the cancer group. When computing subscales for the DASS, the FACT-G, and the spiritual well-being subscale missing data were replaced with the mean score using the automated procedure available on SPSS (Version 16). This practice is consistent with specifications reported in manuals relevant to both the FACIT measuring system, and the DASS.

TABLE 2
IBS Sample - Descriptive Statistics for FACT-G and DASS Scales

	<i>Min</i>	<i>Max</i>	<i>Mean</i>	<i>SD</i>	<i>Skew- ness</i>	<i>Std. Error</i>	<i>Kurtosis</i>	<i>Std. Error</i>	<i>Alpha</i>
AGE	20.00	71.00	44.46	16.26	-.10	.61	-1.33	1.19	
PWB	3.00	28.00	16.99	7.71	-.21	.61	-.94	1.19	.90
SWB	7.00	27.00	19.54	5.97	-.90	.61	.04	1.19	.83
EWB	6.00	22.00	15.69	4.83	-.66	.61	-.46	1.19	.62
FWB	7.00	27.00	17.30	6.72	-.17	.61	-1.23	1.19	.89
SP12	15.00	48.00	31.23	11.17	-.18	.61	-1.39	1.19	.94
FACT-G	49.00	99.00	69.53	17.69	.31	.61	-1.46	1.19	.87
Stress	2.00	35.00	13.53	11.67	.96	.61	-.57	1.19	.95
Anxiety	1.00	35.00	9.50	11.73	1.43	.61	.57	1.19	.96
Depression	.00	37.00	11.53	12.75	1.04	.61	-.40	1.19	.96

PWB: Physical well being; SWB: Social and family wellbeing; EWB: Emotional well being; FWB: Functional well being; SP12, Spiritual wellbeing.

Reliability of scales

As evidenced by the alpha-coefficients shown in Tables 1 and 2, the majority of subscales had acceptable levels of reliability, with alpha-coefficients ranging from 0.71 to 0.96 with the exception of the Emotional Well-Being subscale in the cancer sample where a lower alpha coefficient was indicated ($r = 0.62$).

Normalcy of distributions

In the cancer and IBS samples, and as shown in the statistics reported in the Skewness column of Tables 1 and 2, scores for the stress, anxiety and depression subscales of the DASS were positively skewed; that is, the majority of patients scored relatively lower scores. In the cancer sample, for the FACT-G total scores, and subscale domain scores, excepting the spiritual domain subscale (SP12), the data were negatively skewed: that is the majority of

patients obtained relatively higher scores. These results, with respect to the DASS, have commonly been observed in other studies (i.e. Crawford & Henry, 2003; Lovibond & Lovibond, 1995).

In addition, the cancer sample was not homogenous with respect to their scores on the emotional well-being scale as shown by the higher Kurtosis statistic in Table 1 indicating that data were relatively peaked. Data for the FACT-G total scale were relatively normally distributed. In the IBS sample, as shown in Table 2, all subscales of the FACT-G were negatively skewed. The total scores for the FACT-G were relatively normally distributed.

2.7.4 FACT-G Results: Total Scores

The IBS group had significantly lower scores (Mean = 69.53, $SD = 17.69$) than the cancer group (Mean = 80.50, $SD = 11.49$). A difference of 10.97 points was indicative of a large effect size ($d = .75$) and was clinically meaningful according to criteria specified by Cella, Hahn et al. (2002 and Cella, Eton et al. 2002); and Webster et al. (2003).⁸

2.7.4.1 Hypothesis 1

The cancer group will report lower scores on the quality of life measure (indicative of impairment) as compared with data representative of a healthy population.

Shown in Table 3 are the normative data for the FACT-G scale. An inspection of the means indicates that scores for the FACT-G total scores for the current cancer sample (N=16) are comparable with the US norms, comprising adults with chronic illness, and the normative cancer sample comprised of patients with mixed diagnoses.

⁸ For parsimony, references to clinical significance will refer to the Webster et al. (2003) article.

TABLE 3
Cancer, IBS and US Population Norms for the FACT-G

<i>Sample</i>	<i>Mean</i>	<i>SD</i>
General Population with chronic illness, N = 1075	81.1	18.1
General Population without chronic illness, N = 302	86.8	14.6
Cancer Sample: mixed diagnosis, N = 2236	80.9	17.0
Cancer sub-sample: fully ambulatory without symptoms, N =765	91.0	12.5

Data source: Brucker et al. (2005)

The current cancer sample's scores were lower (6.3 points) than those reported for the US norms without specified chronic illness ($d = .43$)⁹ and were 9.5 points lower than the sub-sample of cancer patients who were fully ambulatory and without symptoms ($d = .71$). These differences exceed Webster et al.'s (2003) cut-offs and are reflective of moderate and large effect sizes (Cohen, 1998). Again, these results indicate clinically meaningful decrements in quality of life scores (Webster et al. 2003).

2.7.4.2 Hypothesis 2

The IBS group will report lower scores on the quality of life measure as compared with data representative of a healthy population.

The IBS sample had scores on the FACT-G measure that were 11.57 points lower than the general population with chronic illness ($d = .63$) and were 17.27 points lower than the general population without chronic illness ($d = 1.28$). These decrements in scores far exceeded Webster et al.'s (2003) criteria for determining statistical and clinical significance.

⁹ Note that for the FACT-G total score comparisons, the effect sizes calculated used the normative population standard deviation for each comparison; this is recommended by Brucker et al. (2005). This method gives a slightly lower effect size.

2.8.1 Comparisons with other chronic illnesses

Limited published data reports on full FACT-G scores for other chronic illnesses.

Nevertheless, one study reporting on the results of patients with HIV ($N = 71$) reported a mean of 72.3 ($SD = 19.9$) (Cella, McCain, Peterman, Mo & Wolen, 1996). The IBS group reported slightly more impairment than the HIV group (Mean Difference = 2.77, $d = .14$). In contrast, the cancer patients reported considerably better quality of life than the HIV group (Mean Difference = 8.2, $d = .50$).

Comparison with Cella et al's (2003) data

Shown in Figure 2 is a summary of the decrements in quality of life observed across a range of chronic illnesses as reported by Cella, Zagari, Vanderos, Gagnon, Hurtz, and Nortier (2003). The data are drawn from the original total US general population without chronic illness. As shown in Figure 2, chronic illnesses such as stroke and anxiety show the greatest level of impairment, with cancer showing similar levels of impairment as compared with diabetes and asthma. Showing the least amount of impairment when contrasted with the general population without chronic illness are conditions such as high cholesterol and back pain.

Comparing the effect sizes calculated in this study with those reported in Figure 2 provides an estimation of the extent of impairment as compared to other chronic illnesses (personal communication with Cella).

The effect size for the IBS group, when comparing mean scores with the same population (i.e. without chronic illness) as Cella et al. (2003) is $d = 1.28$, indicative of a very large effect size. This comparison suggests that the IBS group experience similar decrements in quality of life

as do hepatitis patients. For the cancer group, the effect size is $d = .43$ which equates with a level of impairment comparable with patients with back pain or allergies¹⁰.

NOTE:

This figure is included on page 58 of the print copy of the thesis held in the University of Adelaide Library.

FIGURE 2. Decrements in FACT-G Scores

Source: Cella et al. (2003). Journal of Clinical Oncology, p. 369

Permission to reproduce this figure was gained from the American Society for Clinical Oncology

¹⁰ Cella rescaled the scores to 0 to 100 so direct comparisons are likely to underestimate the extent of disability reported the current study.

2.8.2 FACT-G Subscale Scores

Shown in Table 4, are the means and standard deviations for the FACT-G subscale scores for the IBS and cancer samples, along with the US general population norms, the US cancer norms, and other independent studies.

Highlighted (in bold text) are those mean scores that the current samples show decrements in sub-scale scores as compared with the range of data reported. For the current cancer sample, decrements on the social and well-being scale are indicated. For the IBS sample, decrements on all subscales, excepting the social well-being subscale are indicated.

The level of impairment observed on the emotional well-being subscale in the IBS sample is comparable to the impairment observed in the advanced colorectal cancer sample (i.e. Daugherty, 2005). Note due to amendments that have occurred on the FACT-G measure, data relevant to all subscales are not available.

The current cancer sample show decrements on social and family well-being as compared with the multiple sclerosis group but are comparable to the HIV groups. The IBS sample show decrements on physical well-being, but are higher than one HIV study (Cella et al., 1996) on social and family wellbeing but are comparable on the functional wellbeing subscale.

TABLE 4
IBS, Cancer, and Norms for FACT-G Subscales

	<i>PWB</i>		<i>SWB</i>		<i>EWB</i>		<i>FWB</i>	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Cancer N = 16	22.43	4.08	17.37	5.18	19.25	2.95	21.43	5.05
IBS N = 13	16.99	7.71	19.54	5.97	15.69	4.83	17.30	6.72
US Norms N = 1975	23.0	5.2	19.3	6.8	19.9	5.3	18.9	6.5
US norms: No chronic illness N = 169	24.7	3.8	19.8	6.6	21.8	3.3	20.5	6.2
US Cancer Population Mixed diagnosis N= 2236	21.3	6.	22.1	5.3	18.7	4.5	18.9	6.8
US Cancer Sample Fully ambulatory without symptoms N= 765	25.3	3.4	22.7	5.4	20.1	3.8	22.9	5.6
Mixed Diagnosis Cella, Hahn & Dineen (2002) N = 308	21.2	6.2	22.3	4.8	18.1	4.5	18.8	6.4
Mutiple Sclerosis Chang, Cella & Fernandez et al (2002) N=625			20.5	5.0	19.7	6.7		
HIV Cella, McCain & Peterson, Mo & Wolen (1996) N = 71	17.4		17.2		14.4		16.5	
HIV Peterman, Cella, Mo and McCain (1997) N = 257			21.4		20.4			

2.8.3 Spiritual Wellbeing

Means and standard deviations for the cancer and IBS samples for the spiritual subscale, the SP12, are shown in Table 5. An inspection of the mean scores on this measure indicates that both current study samples have lower scores than the advanced cancer samples and normative samples comprised of cancer patients, however, they are higher than the scores reported for a group of palliative care workers and a group of cancer patients with mixed diagnoses.

As indicated by the effect sizes shown in Table 5, both the cancer and IBS samples report significantly lower levels of spiritual wellbeing as compared with the advanced colorectal cancer groups.

TABLE 5
Spiritual Wellbeing: Cancer, IBS, and Independent Studies

	<i>Mean</i>	<i>SD</i>	<i>Cancer</i>		<i>IBS</i>	
			Mean	Effect	Mean	Effect
			Diff	size	Diff	size
Palliative Care Workers (Wasner et al. 2005), N = 59	25.5	*	6.7		5.73	
Cancer Colorectal (Daugherty et al, 2005), Sample 1, N =162	40.7	7.2	8.5	1.19	9.47	1.03
Cancer Colorectal Daugherty et al (2005) Sample 2, N= 156	39.7	7.2	7.5	1.05	8.47	0.92
Mixed Diagnosis, predominantly breast (Garland et al. 2007) N = 104	29.7	8.59	2.5	0.31	1.53	0.15
Mixed Diagnosis (Peterman et al.,2002), N= 1,617	38.5	8.1	6.3	0.83	7.27	0.75

*SD not provided in journal article

2.8.4 DASS Results

Cancer patients as compared with normative data

Means and standard deviations for the cancer and IBS samples in the current study are shown alongside the normative reference data shown in Table 6. Data relevant to two general population samples were used as comparisons. The Australian University sample is the main sample that has been used in comparisons using the DASS, however, Crawford and Henry (2003) propose that the University sample may not be appropriate because higher levels of depression have been observed in previous research in this sample. Thus, Crawford and Henry (2003) have collected normative data from the community which may be more representative of the general adult population. Note though this data is from the United Kingdom. Also included is another sample comprised of Australian adults with chronic pain (Nicholas, Asqhari & Blyth, 2008).

TABLE 6
DASS Scales: Normative Data Compared with Cancer and IBS Samples

	<i>Stress</i>		<i>Anxiety</i>		<i>Depression</i>	
	Mean	SD	Mean	SD	Mean	SD
Cancer	7.06	5.06	4.33	5.92	4.80	7.44
IBS	13.53	11.67	9.50	11.73	11.53	12.75
Normative Reference (Lovibond & Lovibond, 1995)	6.34	6.97	4.70	4.91	10.11	7.91
Chronic Pain (N=5,941) Nicholas, Asqhari, & Blyth (2008)	16.26	11.23	9.27	8.64	14.29	11.95
Crawford & Henry (2003) N=1,771	9.27	8.04	3.56	5.39	5.55 (7.98)	7.98

Severity of distress

According to the severity ranges described by Lovibond and Lovibond (1995), the cancer sample in this study fall in the normal range with respect to levels of depression, anxiety and stress. In contrast, the IBS sample fall in the mild range in terms of anxiety and depression, and in the normal range for stress.

Levels of distress – cancer versus IBS

When compared to the cancer group, the IBS group reported significantly higher scores on the stress scale (Mean difference 6.47, $d = .77^{11}$), anxiety scale (Mean difference = 51.7, $d = .58$), and depression scale (Mean difference = 6.73, $d = .66$)

2.8.4.1 Hypothesis 3

The cancer group will report higher scores on each of the distress measures (indicative of increased distress) as compared with general populations

The results indicate that the cancer sample when compared with the University sample (Lovibond & Lovibond, 1995) had slightly higher levels of stress (Mean difference .72, $d = .11$), similar levels of anxiety (Mean difference = .37, $d = .03$) and were significantly lower on the depression subscale (Mean difference = 5.31, $d = .69$).

When compared with the community sample, the cancer sample reported slightly higher levels of anxiety (Mean difference = .77, $d = .13$), and lower levels of stress (Mean difference 2.21, $d = .29$) and similar levels depression (Mean difference = .75 $d = .09$).

When compared with the chronic pain sample (Nicholas et al., 2008), the cancer group reported significantly lower levels on stress (Mean difference = 9.20, $d = 1.13$), anxiety (Mean difference = 4.94, $d = .67$) and depression (Mean difference = 9.49, $d = .98$).

¹¹ All effect sizes were calculated using the pooled standard deviations (i.e. Cohen's $d = M_1 - M_2 / \sigma_{\text{pooled}}$ where $\sigma_{\text{pooled}} = \sqrt{(\sigma_1^2 + \sigma_2^2) / 2}$)

2.8.4.2 Hypothesis 4

The IBS group will report higher scores on each of the distress measures (indicative of increased distress) as compared with general populations.

Compared to the University sample, the IBS group reported significantly higher levels of stress (Mean difference = 7.19 $d = .77$) higher levels of anxiety (Mean difference = 4.80, $d = .57$) and slightly higher levels of depression (Mean difference = 1.42 $d = .17$).

When compared with the community sample, they reported higher levels of stress (Mean difference = 4.26, $d = .39$) anxiety (Mean difference = 5.94, $d = .69$) and depression (Mean difference = 5.98, $d = .57$).

However, when comparing the IBS group to the chronic pain sample (i.e. Nicholas et al., 2008), the IBS group reported less impairment in terms of depression (Mean = 2.76, $d = .22$) and stress (Mean difference = 2.73, $d = .25$). They reported comparable levels of anxiety (Mean difference = .23, $d = .02$).

2.8.4.3 Hypothesis 5

In both groups, scores on the distress measures will be negatively associated with scores on the quality of life measure

Complete tables of inter-correlations among study variables are provided in Appendix D for the cancer and IBS samples.

Cancer sample

In the cancer sample, stress, ($r = -.70, p < .01$), anxiety ($r = -.64, p < .01$) and depression ($r = -.67, p < .01$) were negatively correlated with FACT-G total scores. Stress scores, but not anxiety or depression scores, were negatively correlated with scores on the emotional well-

being subscale ($r = -.58, p < .05$). Scores on the stress ($r = -.67, p < .01$) anxiety ($r = .51, p < .05$) and depression ($r = -.74, p < .05$) scales were correlated with scores on the functional well-being subscale. Depression scores ($r = -.65, p < .01$) but not anxiety or stress scores were negatively correlated with scores on the physical well-being subscale.

Months since diagnosis, but not age, was negatively correlated with total FACT-G ($r = -.71, p < .01$) total scores, social and family well-being ($r = -.57, p < .05$) and functional well-being ($r = -.58, p < .05$) scores. Religious involvement was negatively correlated with social and family well-being ($r = -.65, p < .05$), and religious involvement was positively correlated with the spiritual well being scale ($r = .62, p < .05$).

IBS sample

Levels of distress, in particular anxiety ($r = -.53, p < .05$) and stress ($r = -.72, p < .05$) but not depression were negatively correlated with FACT-G total scores. Stress ($r = -.56, p < .05$) and anxiety ($r = -.57, p < .05$) but not depression were negatively correlated with subscale scores for physical well being. Involvement in religion was not correlated with the spiritual domain subscale, however, age was ($r = .62, p < .05$).

2.9 Discussion

2.9.1 Overview of Results

The aim of this study was to obtain descriptive data relevant to providing an estimate of patients' perceptions of levels of distress and disability experienced. Specific hypotheses were proposed and 4 of the 5 hypotheses were supported. For instance, both IBS and cancer patients reported impaired quality of life as compared with a general 'healthy' population. However, only the IBS group reported increased distress as compared with both general populations. Hypothesis 5 was supported: In both groups, distress scores were negatively associated with quality of life scores.

Other results indicated that the IBS group reported significantly more disability than the cancer sample as evidenced by elevated scores on each of the DASS subscales (i.e. stress, anxiety, depression) and markedly lower scores on the FACT-G scale.

2.9.2 Background and Aims

The focus of this study was on identifying the nature and extent of disability in the cancer sample compared with the IBS sample and other chronic illnesses using validated measures of distress (DASS; Lovibond & Lovibond, 1995) and quality of life (FACT-G; Cella, 1997). Assessments concerning levels of distress experienced were based on comparisons with available normative data (Brucker et al. 1995) and published severity ranges (Lovibond & Lovibond, 1995). Judgements concerning clinical significance of differences in quality of life scores were based on data reported by Webster et al. (2003). Similarly, assessments of statistical significance were based on the calculation of effect sizes. This approach is consistent with recommendations reported by Brucker et al. (2005).

2.9.3 Summary of Results FACT-G

IBS versus cancer sample

Results indicated that the IBS patients reported considerably more disability than the cancer group as indicated by markedly decreased scores on the FACT-G measure. The extent of the difference between the IBS group and the cancer group was reflective of a large effect size and was clinically meaningful as indicated by a difference in total FACT-G scores of more than 3-7 points (Webster et al., 2003).

IBS and cancer samples as compared with other chronic illness

The cancer participants reported levels of quality of life that were similar to a general population comprised of individuals with other chronic illnesses, although their levels were lower than those of a general healthy population without chronic illness (Brucker et al., 2005),

and significantly lower than a sample comprised of cancer patients who were fully ambulatory and without symptoms. Each of these comparisons yielded clinically meaningful differences and were indicative of a small (i.e. general population with no chronic illness) and a moderate (fully ambulatory sample) effect size. Compared with Cella et al.'s (2003) data their level of impairment was similar to individuals with allergies and back pain.

Previous research showed that IBS patients reported reduced quality of life as compared with a range of chronic illnesses including panic disorder, rheumatoid arthritis, migraine and asthma (Frank et al. 2002). Results reported in this study replicate these findings. For example, when compared with data by Cella et al. (2003), the IBS group reported more disability than patients with depression, heart disease, anaemia, carpal tunnel syndrome, cancer, diabetes, asthma, ulcers, acid reflux, hypertension, arthritis, allergies, back pain and high cholesterol. Comparing, the extent of their disability, the IBS group reported impairments in quality of life comparable with hepatitis patients (Cella et al., 2003).

2.9.4 FACT-G Subscale Scores

IBS and cancer samples compared with other chronic illnesses

When assessing sub-domains of the FACT-G and the spiritual wellbeing scale (Peterman et al., 2002), the results indicated that IBS patients had lower scores on physical wellbeing compared with patients with HIV (Cella et al., 1996) and they were lower on emotional wellbeing than a sample of multiple sclerosis patients (Chang et al. 2002). Levels of emotional impairment in the IBS group were similar to a sample of advanced colorectal cancer patients (Daugherty et al., 2005).

The cancer sample showed decrements on the social and family wellbeing scale, as compared with population norms. This finding was consistent with the Cella and Hahn et al. (2002) study whereby patients with mixed diagnoses reported lower scores on the social and family

wellbeing scale when compared to a healthy population. Scores on the social and family wellbeing scale were also lower than those reported in studies with patients with multiple sclerosis (Chang et al., 2002) and HIV (Cella et al., 1996). The extent of these impairments (i.e. whether or not they were clinically meaningful) could not be determined as reference ranges are not yet available for the social and family wellbeing scale.

When considering scores on the spiritual well-being scale, both the IBS sample and the cancer sample had comparable levels but were significantly lower than other cancer samples (Daugherty et al., 2005; Peterman et al., 2002) but higher than palliative care workers (Wasner et al., 2005). In this study, religious involvement was correlated with spiritual wellbeing in the cancer group but not the IBS group. Future research might seek to establish whether cancer patients seek out religious involvement following the diagnosis of cancer.

2.9.5 Summary of Results: DASS

IBS versus cancer sample

IBS patients reported considerably more distress than the cancer patients as indicated by higher scores on each of the DASS (Lovibond & Lovibond, 1995) subscales (e.g., stress, anxiety and depression). Indeed, levels of anxiety and stress were twice as high and levels of depression were three times as high in the IBS group as compared with the cancer group.

IBS and cancer samples as compared with normative data and a chronic pain sample

The cancer patients reported 50% lower levels of depression than Lovibond and Lovibond's (1995) University sample but they were comparable in terms of anxiety and stress. When compared with the other general population (Crawford & Henry, 2003), levels of stress and depression were lower in the cancer population but levels of anxiety were slightly higher. Compared with a chronic pain group (Nicholas et al., 2008), they reported approximately 75% lower scores on depression, were slightly lower on stress and comparable on anxiety scores (Nicholas et al., 2008).

IBS patients reported levels of stress that were twice as high as the University sample (Lovibond & Lovibond, 1995), and considerably higher than the general population (Crawford & Henry, 2003) but lower than the chronic pain sample (Nicholas et al., 2008). They reported higher levels of anxiety than the general and student populations. Levels of anxiety were comparable with the chronic pain group but they were slightly lower on depression. In fact, the depression scores for the IBS group were only marginally higher than the student population but were twice as high as the scores reported for the other general population¹².

2.9.5 Relationship Between Distress and Quality of Life

In both groups, distress scores were negatively correlated with FACT-G total scores providing some preliminary support for the hypothesis that psychological distress may impact on levels of disability. Although it is also possible that diminished quality of life may lead to the development of mental disorders such as anxiety and/or depression (Prince et al., 2007). Nevertheless, indices of distress were differentially associated with sub-domains of quality of life. For example, stress was associated with emotional wellbeing; depression with physical wellbeing; and, stress, anxiety and depression with functional wellbeing.

With respect to the cancer patients, and in support of the claim that disability is experienced for a considerable time after entering remission, FACT-G scores were negatively correlated with months since diagnosis. Indeed, the majority of patients in this study were in remission and for many patients a considerable time had elapsed since their initial diagnosis. As was shown by the negative correlation between FACT-G scores and the number of months since

¹² A disparity between scores in the general population versus the student population exists. It is unknown whether this difference reflects cultural differences between Australian and English samples or whether the difference reflects differences in incidence/reporting of depression in community versus University samples. It appears that further validation work is required to enable meaningful comparisons.

diagnosis, patients tended to perceive more disability (i.e. impairments in quality of life) the longer the elapsed time since their initial diagnosis.

In other words, and albeit indirectly, there is some support for previous research showing that cancer patients continue to experience distress and impaired quality of life for many years after entering remission (Wenzel, et al., 2005). The average time since diagnosis in this study was approximately four years which is consistent with previous research that suggests that impairments in quality of life are still measurable at this period, in contrast to longer periods of 10 to 15 years (Mols et al., 2006)

In the IBS group, stress and anxiety (but not depression) were strongly and negatively correlated with the physical wellbeing subscales, and the overall FACT-G scores. These findings are consistent with Drossman's conceptual model (1998) whereby stress and anxiety are linked with reduced quality of life.

2.9.6 Implications of Results

Estimates of disability and issues of co-morbidity

When judging the extent of impairment experienced, it is usual to compare overall quality of life scores reported by chronic illness samples with those reported by general populations. However, researchers and clinicians should be careful to ensure that these general populations comprise 'healthy' individuals. For instance, given the high prevalence of chronic illness in the 21st century, particularly in populations aged over 60, then comparisons concerning the extent of impairment when compared with these populations are likely to underestimate the level of impairment. Individuals with chronic illnesses experience considerable distress and often have co-morbid psychological disorders including depression and anxiety (Prince et al., 2007). Thus, comparisons with chronic illness groups may give an inflated estimate of actual functioning.

For example, when the current cancer sample was compared with the general population ‘with chronic illness’ no meaningful or statistical difference was observed. In contrast, when comparing the current sample with the healthy population (i.e., ‘without chronic illness’) then the difference was significant and meaningful.

In this study, both groups of participants reported a range of other chronic conditions. Thus from a methodological point of view, it may be difficult to determine the amount of disability that occurring as a result of cancer, versus the disability occurring as a result of other chronic conditions. In this respect, perhaps it may be more appropriate to compare quality of life scores with samples comprised of individuals with chronic illness. Any disability experienced over and above that of the chronic illness group could be attributed to cancer.

Adequacy of chronic distress measure

Previous research suggests that receiving a diagnosis of cancer is associated with significant distress (Classen et al., 2001; Pascoe et al., 2000) and this distress can, reportedly, continue for many years following the acute stage of the illness (Deimling et al., 2002; Jefford, Black, Grogan, Yeoman, White & Akkerman, 2005). Research has not examined at what point, if ever, levels of distress (presuming they occur as a result of the diagnosis of cancer) return to baseline levels. Although, as noted research suggests that cancer survivors report higher levels of quality of life 10 to 15 years into survivorship, as compared with 5 to 9 years (Mols et al., 2006).

Admittedly, it is difficult to determine the extent to which psychological distress and or emotional states such as anxiety and/or depression occur as an outcome of cancer. For instance, many studies assume that distress reported occurs as a direct consequence of cancer; however, in these studies patients may have met criteria for psychological disorder prior to the onset of cancer. For instance, there is some evidence that having a mental disorder, such as

depression, puts one at risk for physical illnesses such as coronary heart disease and cancer. For example, Prince et al. (2007) reviewed the prospective studies that showed a link between mental disorders and physical illness. It has also been claimed that depression predicts later onset of cancer (Spiegel & Giese-Davis, 2003).

Currently, considerable gaps in knowledge exist concerning the nature, extent, and course of distress that occurs throughout the cancer experience. As reviewed, cancer patients reported levels of distress that were lower than levels reported in the general population (Crawford & Henry, 2003, Lovibond & Lovibond, 1995). An explanation for the lower than expected levels of distress reported in this study could be that the measure of distress (i.e. the DASS) did not capture the nature of distress experienced by the cancer patients. Segerstrom and Miller (2004) suggest that different kinds of stress (i.e. acute versus chronic) are associated with differential outcomes. An assessment of whether an acute measure of stress may better reflect the nature of distress experienced by cancer patients will be performed in Chapter 3.

Cancer patients may underestimate levels of distress

Whilst it is possible that the current cancer sample may be exceptionally well adjusted, this finding may also be attributed to a general tendency observed in previous studies whereby cancer patients show a tendency to underestimate their levels of distress. For example, Kneir and Tomosok (1984) measured the skin conductance responses (SCR) of cancer patients and compared the SCR responses of cancer patients with a group of patients diagnosed with cardiovascular disease (CVD), and with a healthy patient group. Slides containing 50 anxiety provoking statements were flashed in front of each participant. The statements were designed to elicit affective responses such as anger, sadness and anxiety. Participants in each group were then asked to rate the extent to which the statement bothered them. These ratings were then compared with the intensity of the SCR responses observed. Results indicated that the cancer patients demonstrated more intense SCR responses indicative of higher levels of

distress than the other groups. But, when the cancer patients were asked to rate the extent to which the anxiety provoking statements bothered them they expressed significantly less emotional upset than the CVD and healthy groups. In Chapter 4, the construct of inhibition will be explored as a potential mechanism to explain the low levels of distress reported by cancer patients in this study.

2.9.7 Limitations

There are several limitations that may impact on the reliability and validity of comparisons made in this study, and potentially other studies seeking to compare quality of life scores across chronic illness groups. For example, a major difficulty was encountered when attempting to gain valid data on the FACT-G for other chronic illness groups. The data provided in Figure 2 were based on the original internet survey when all data that comprised the US general population ‘normative’ reference group were collected (see Cella et al., 2003). The allocation of patients into chronic illness versus no chronic illness was based on participants’ self-reports and not on a formal medical diagnosis. Moreover, according to Cella (personal communication) responders in internet surveys are notorious for overestimating their scores on quality of life measures. Therefore, discrepancies observed between the chronic illness groups and the IBS and cancer samples may be larger than reported.

Lent et al. (1999) suggest that the FACT-G has been validated in chronic illness groups such as Parkinson’s Disease, Rheumatoid Arthritis and Multiple Sclerosis. In reality, ‘validity’ studies with respect to using the FACT-G have not occurred for Rheumatoid Arthritis or Parkinson’s Disease, or at least these studies have not been published. Data for the Multiple Sclerosis group were only comparable on two subscales (i.e. social/family wellbeing, and emotional wellbeing). Other items that form the basis of the quality of life measure for the MS group were disease specific. Older data relevant to an HIV group were available,

however, newer versions of the FACIT measuring system have amended items so that the measure is also disease specific.

Other limitations pertain to this specific study. In particular, the small sample and the sampling method (i.e., an opportunity sample) limit the generalisability of the results to the wider population of cancer patients.

2.9.8 Conclusion

In conclusion, this study provided descriptive data relevant to providing estimates of patients' perceptions of disability as measured by validated measures of quality of life and distress.

The results indicated that individuals with a non-organic condition (IBS) reported significantly more distress and markedly impaired quality of life as compared with a condition with a known organic cause. Cancer patients reported levels of distress that were lower than both general populations and significantly lower than a chronic pain sample. As reviewed, the concept of 'emotional inhibition' may assist in providing an explanation for the lower than expected levels of distress reported by the cancer patients. The emotional inhibition concept will be reviewed in Chapter 4. In Chapter 3, an additional measure of distress will be incorporated with the aim of continuing to develop an understanding of the extent and/or nature of disability experienced by cancer patients.

3 CANCER: ACUTE OR CHRONIC STRESS?

Researchers suggest that measures that reflect the impact of acute stress, "... may better reflect the emotional impact of cancer than mere assessments of such emotions such as depression or anxiety" (Tjemslund, Soreide & Malts , 1996, p. 2). Thus, in this study, the aim is to continue to investigate distress with an emphasis on the type of distress potentially experienced by cancer patients. In this chapter, a synopsis of Segerstrom and Miller's (2004) review linking different kinds of stressors with adverse outcomes is provided. Also described are theories that attempt to explain the possible mechanism(s) linking stress with disease. Also provided is a review of literature that suggests that cancer patients experience an 'acute' stress response following the diagnosis of cancer. This involves a review of research that assesses the impact of stress incurred as the result of a traumatic experience using the Impact of Event Scale (Horowitz et al., 1979).

3.1 A Review of Stress Research

3.1.1 Dominant Theory of Stress

For many years, the major influence in terms of understanding how 'stress' impacts on health was Hans Seyle (1976). According to Seyle (1976), stress has a generalised and suppressive effect on immune function. He proposed that this suppressed effect of immune function could account for the heightened incidence of infection and disease observed in stressed populations (Segerstrom & Miller, 2004). Specifically, Seyle (1976) described this view of stress and its impact on health via the General Adaptation Syndrome (GAS). According to this theory, the human body responds in three stages following the onset of a stressor. First, the 'alarm reaction' mobilises the sympathetic division of the autonomic nervous system (i.e. the fight or flight response). Neurotransmitters such as adrenaline (epinephrine) and noradrenalin (norepinephrine) and hormones including corticosteroids such as cortisol are released. Resistance refers to the second stage whereby the body attempts to resist the continued onset

of the stressor. In this stage, an individual may not necessarily be consciously aware of the stressor. During this stage - and with repeated exposure to the stressor- physiological changes are occurring in the body. For instance, damage to the systems of the body is occurring and the body's reserves of carbohydrates and fats are being depleted. This is the stage whereby certain 'diseases of adaptation' occur (e.g., hypertension, diabetes and eczema). In the third and final stage, 'exhaustion' is said to occur. This is when the body's reserves are depleted and extensive damage to the organs, cardiovascular systems and/or immune functioning occur (Seyle, 1976).

3.1.2 Alternative Theories of Stress

As reviewed by Segerstrom and Miller (2004), this view of the stress process was contested in the late '90s when Dhabhar and McEwen (1997, 2001) proposed a bi-phasic model. They discounted Seyle's (1976) model on the basis that the immunosuppressive idea was largely inconsistent with notions of human adaptiveness and survival. In the bi-phasic model, Dhabhar and McEwen (1997, 2001) distinguish between 'chronic' and 'acute stress' and suggest that differential responses occur, in an adaptive manner, depending on the nature of the stressor. For example, they predict that in response to acute stress, the fight and flight response (and accompanying sympathetic nervous system activation) would result in a rapid redistribution of immune cells to areas where they were needed. In support of this model, a series of studies involving mice exposed to acute stress showed an enhanced immune response. Dhabhar and McEwen (1997, 2001) further predicted that mice exposed to 'chronic stress' would demonstrate a suppressed immune response. Results confirmed their predictions.

A third model proposes that chronic stress has a dysregulating effect on immune function: stress is thought to enhance some aspects of immune function while diminishing others. Support for this model was shown when following exposure to chronic stress changing

patterns of cytokine secretion were observed (Marshall, Agarwall, Lloyd, Cohen, Henniger & Morris, 1988).

3.1.3 Different Stressors have Differential Impacts on Wellbeing

Importantly, as reviewed by Segerstrom and Miller (2004), different kinds of stressors appear to have differential impacts on the human immune system. For instance, 85 studies involving acute-time limited stressors were identified in their review. The majority of these studies involved experimental manipulation of acute stress (e.g., performing arithmetic, public speaking) and lasted between 5 and 100 minutes. According to the authors, the findings support Dhabhar and McEwen's (1997; 2001) bi-phasic modal model that suggests that acute stress results in the redistribution of immune cells with reliable effects observed on several immune parameters, largely reflective of natural immunity. The most robust effects noted were an increase in the number of natural killer cells and large granular lymphocytes. No consistent effects were observed on other types of cells.

A further 63 studies investigated brief naturalistic stressors in healthy adults. Typically, the samples involved university students and the naturalistic stressor observed involved students facing exams. No changes in percentages of cells were identified but "changes in cytokine production that indicate a shift away from cellular immunity (Th1) and a shift toward humoral immunity (Th2)" were found (Segerstrom & Miller, 2004, p. 612). Thirty studies involving a stressful event sequence were identified. Events included the death of a spouse; a positive result following a biopsy for breast cancer; and exposure to a disaster. NK cells increased, as did numbers of antibodies to the Latent Epstein-Barr virus, however, no other reliable changes in other immune parameters were observed. When data were re-examined to focus exclusively on older adults (aged over 55), significant changes were observed.

Twenty three studies involving 'chronic stress' were identified. Examples of chronic stress included: dementia care-giving, living with a handicap, and unemployment. Results

indicated that while no changes were seen in the numbers or percentages of cells, virtually all functional immune parameters showed significant decrements. Segerstrom and Miller (2004, p. 614) report the following:

Increasing stressor duration, therefore, resulted in a shift from potentially adaptive changes to potentially detrimental changes, initially in cellular immunity and then in immune function more generally ... [C]hronic stressors maybe less controllable and afford less hope for control in the future. These factors could contribute to the severity of the stressor in terms of the psychological and physiological impact.

Segerstrom & Miller, 2004, p. 614

3.2. Acute Stress Reactions in Cancer Samples

In Segerstrom and Miller's (2004) paper, the major studies reviewed involving 'acute stress' involved experimental manipulation of the stressor. Other studies focus on acute stress occurring as a result of exposure to a traumatic event. According to research conducted in the United States, 2 to 19% of cancer patients satisfy the criteria for Acute Stress Disorder (ASD; Classen, et al. 2001). Further, in a review of the incidence of cancer-related Post Traumatic Stress Disorder (PTSD), Kangas, Henry and Bryant (2002) suggest that incidence rates range from 0% to 32%. Moreover, in a study of patients diagnosed with lung, head, and/or neck cancer, 28% of patients were diagnosed with ASD during the month following diagnosis. Of these 53% of patients met the full criteria for a diagnosis of PTSD when reassessed 6 months later. According to Classen et al. (2001), even when patients do not meet all criteria for a diagnosis of PTSD, many patients experience clinically relevant symptoms that result in significant impairments in social functioning and quality of life.

3.2.1 Acute Stress Reactions and the Impact of Event Scale

Traumatic events usually prompt distress, and efforts to cope can manifest in an individual being unable to stop thinking about the event, or to consciously avoid these thoughts.

McBride, Clipp, Peterson, Lipkus, Demark-Wahnefried, 2000, p.419

The presence of distress, as measured by the original version of IES scales is conceptualised as the presence of intrusive thoughts and/or avoidance of thoughts with respect to the particular trauma. In other words, the measure attempts to capture the clinical criteria, as per the DSM-IV-TR (APA, 2000) relevant for a diagnosis of PTSD. A second version of the IES was created to counter criticism that the scale did not capture all symptoms relevant to a diagnosis of Post Traumatic Stress Disorder (IES-R, Weiss & Marmar, 1997). The IES-R incorporates a further subscale, hyper-arousal. Hyper-arousal refers to symptoms involving increased arousal such as a) difficulty falling or staying asleep b) irritability or outbursts of anger c) difficulty concentrating d) hyper-vigilance e) exaggerated startle response.

The IES-R measures symptoms that occur, presumably as a result of acute stress, following the experience or the witnessing of an event whereby a threat of death or serious injury occurred. A range of studies incorporate the IES, or the IES-R to assess for the presence of symptoms relevant to a diagnosis of PTSD, and have included a range of traumatic events. These include events involving injury and illness, natural disaster, technological disaster, bereavement and loss, violence and threat, sexual abuse, and war exposure. In Sundin and Horowitz's (2003) review, the worst outcomes (i.e. the highest levels of symptoms) were observed in relation to trauma experienced as a result of war and sexual abuse.

Studies have reported the presence of symptoms of intrusion and/or avoidance in a variety of chronic illness samples, including breast cancer (Alter, Pelcovitz, Axelrod, Goldenberg, Harris, Myers et al., 1996; Andrykowski & Cordova, 1998; Butler, Koopman, Classen &

Spiegel, 1999; Cordova et al., 1995); Huntington's disease (Tibben, 1994); Hodgkin's disease (Cella & Tross, 1986); myocardial infarction (Baumert, Simon, Gundel, Schmitt, Ladwig, 2004); and, mixed types of cancer (Alter et al. 1996; McGarvey et al., 1998).

Previous research suggests that psychological reactions to receiving a diagnosis of cancer can be highly variable (McBride et al., 2000). Stress reactions and/or impairments noted vary according to a range of demographic characteristics (e.g. income, education and gender) and medical characteristics (type of cancer and type of treatment) and psychosocial factors (e.g., available social support) (Cella and Tross, 1986; Horowitz et al., 1979; Kornblith et al., 1992). In a meta-analysis of studies conducted over a 20 year period neither age nor gender had an impact on levels of distress observed, as measured by the IES (Sundin & Horowitz, 2003).

McBride et al. (2000) suggest levels of distress vary as a consequence of time, with generally less distress observed the greater the time since diagnosis. This finding is not applicable across all types of cancer diagnoses and for some types of cancer, particular those involving a change in physical appearance, or impaired sexual function, distress may continue for extended periods of time (McBride et al., 2000). The issue of time and its role in reduced levels of distress is not completely understood and inconsistent results exist. For instance, in Sundin and Horowitz's (2003) review, they reported increasing IES scores (i.e. increasing distress) as a function of time when comparing studies that used a cross-sectional design. In contrast, and when evaluating studies that incorporated a follow up assessment (i.e. a longitudinal design) stress scores decreased with time.

Different results may be a function of other variables. For instance, in studies involving cancer survivors, scores on the IES were positively correlated with a fear of a recurrent diagnosis (Black & White, 2005). This finding may suggest a different source of stress. For

example, cancer patients may experience an initial acute stress reaction at diagnosis, however, they may also experience ongoing stress experienced as a result of fearing a diagnosis of recurrence (Koopman, Butler, Classen, Giese-Davis, Morrow, Westendorft et al., 2002).

3.2.2 Applicability of Trauma Concept in Cancer Populations

Although the IES has been widely used in cancer samples, some commentators query the validity of this approach. For example, they argue that receiving a diagnosis of cancer is conceptually different to experiencing other types of life-threatening trauma (Green, Epstein, Krupnik & Roland, 1997). Critics argue that the origin of the trauma in cancer is internal to the individual whereas in other life-threatening events, the origin of the trauma is external to the individual (Koopman et al., 2002). Furthermore, in other life-threatening traumas, the event that an individual is typically reporting occurred in the past. Though, Koopman et al., (2002, p. 278) suggest that the impact may be more extreme in cancer and argue that "... given the chronic nature of being diagnosed with, treated for, and living with cancer it may entail both a threat to life and an ongoing threat to quality of life".

3.3 Summary and Aims

In applying the knowledge gained from Segerstrom and Miller's (2004) review of stress, particularly in terms of understanding how different forms of stress can impact on health in different ways, it appears that further assessment of the type/nature and extent of distress experienced by the current cancer sample is warranted. For instance, the IES might provide a more sensitive assessment in relation to any distress experienced. Patients living with cancer frequently face situations they could perceive as life-threatening (i.e., at diagnosis, prior to treatment such as invasive surgery, or aversive therapy such as chemotherapy and/or radiotherapy). Thus, the IES may tap aspects of stress that differ from those captured by measures designed to assess the impact of low level chronic stressors such as the DASS. On the basis of this review, and in accord with previous research, the following hypotheses are proposed:

3.3.1 Hypotheses

- H1: Mean scores for the total IES and IES-R scales will be elevated at levels comparable with other samples exposed to a traumatic event.
- H2: IES-R scores will be negatively correlated with quality of life scores
- H3: IES-R subscales will be better predictors of quality of life scores as compared with the DASS scales.

3.4 Method

3.4.1 Participants

Thirteen participants with a history of cancer (e.g. time since diagnosis ranged from 6 months to 13 years, $SD = 43.53$) and three patients with a current diagnosis of cancer participated in this study¹³. There were 11 females (Mean = 55.27, $SD, 8.69$) and 5 males (Mean = 59.40, $SD, 9.65$) who had previously received a diagnosis of cancer. A full account of the demographic and medical characteristics of participants was provided in Chapter 2.

3.4.2 Measures

Post-traumatic stress disorder symptoms

The Impact of Event Scale, Revised (IES-R, Weiss & Marmar, 1997) comprises a 22 item scale that assesses symptoms of Post Traumatic Stress Disorder, according to 3 dimensions, including intrusion, avoidance, and hyper-arousal symptoms. Examples of statements include: “Any reminder brought feelings back about it”, “I avoided letting myself get upset when I thought about it or was reminded of it” and, “I was jumpy and easily startled”.

Items were scored on a Likert scale from 0, “not at all” to 4, “extremely”. Internal consistency of subscales were reported by Briere (1997) with alpha’s for intrusion ranging from 0.87 to .92; for avoidance 0.84 to 0.86; and, for hyper-arousal 0.79 to 0.90. Wiese and Marmer (1997) report test re-test correlation coefficients of around .60 for all subscales in

¹³ These 16 participants were also those that participated in Study 1 (see chapter 2).

Study 1 (N = 429); however, in Study 2 (N = 197) all correlation coefficients were above .90. In the second study, there was a shorter interval between assessments, and the traumatic episode occurred more recently.

Items in the IES- R are based on the clinical criteria relevant to receiving a DSM-IV-TR (APA, 2000) diagnosis of PTSD; the IES-R extends upon the IES (Horowitz et al., 1979) as this measure does not include items relevant to the DSM-IV criteria concerning symptoms of hyper-arousal. Severity ranges with respect to estimating the extent of distress are reported by Horowitz (1982). These are used to assess the extent of distress in the current cancer sample.

Quality of life and distress (stress, anxiety, depression)

Specific details concerning the FACT-G and DASS scales were reviewed in Chapter 2.

3.5 Results

3.5.1 Missing data, Normalcy and Reliability

Missing data for all key variables were minimal: Two items on the IES-R had missing scores. These were replaced with the automated procedure on SPSS. Data were assessed for normalcy and no significant deviations were noted. Although as shown in Table 6, the avoidance subscale of the IES-R, was slightly negatively skewed indicating that scores were generally higher on these measures. As shown by the negative kurtosis statistic, the scores on total scales and subscales were non-peaked except for the avoidance subscale of the IES. As shown by the alpha co-efficient reported in Table 7, the IES-R had good internal consistency, as did the IES subscales, intrusions and hyper-arousal. Lower reliabilities were found for the IES scale and the avoidance subscale.

TABLE 7
Descriptive Statistics, IES, IES-R and Subscales

	<i>Avoidance</i>	<i>Intrusions</i>	<i>Hyper- arousal</i>	<i>IES</i>	<i>IES-R</i>
Mean	7.75	6.42	3.87	14.17	18.05
Std. Deviation	4.29	5.28	4.31	8.42	12.10
Skewness	-.02	.862	.94	.31	.57
Std. Error of Skewness	.56	.564	.56	.56	.56
Kurtosis	-1.43	.453	-.35	-.69	-.60
Std. Error of Kurtosis	1.09	1.09	1.09	1.09	1.09
Minimum	2	0	0	2	2
Maximum	14	19	13	31	42
Alpha	.67	.90	.87	.69	.83

IES: Impact of Event Scale comprises total scores of the avoidance and intrusion subscales; IES-R comprises total scores of the avoidance, intrusion and hyper-arousal subscales. Higher scores indicate higher levels of stress symptoms. A score of 0 indicates the absence of stress symptoms.

3.5.2 IES, IES-R and Subscales

Severity of distress

According to published severity ranges (see Horowitz, 1982; Tjemsland et al., 1996) nine participants (56.25%) scored in the low range and seven (43.75%) scored in the moderate range on the avoidance subscale. For the intrusion subscale, 11 participants (68.75%) scored in the low range and five (31.25%) scored in the moderate range. Using the cross-tabs procedure on SPSS, patients with higher scores had the following diagnoses: head and neck (N = 3), lung (N = 1), acute myeloid leukaemia (N = 1), and non-Hodgkin's lymphoma (N = 1). The Non-Hodgkin's lymphoma participant had also received a diagnosis of recurrent breast cancer. Again, using the cross tabs procedure on SPSS, results indicated that 5 of these patients had received their initial diagnoses at least 4 years ago, whilst the other diagnosis was received 16 months ago.

Table 8 shows the means and standard deviations for the cancer sample as compared to scores reported following exposure to a range of traumatic experiences.

TABLE 8
IES and IES-R and Subscale Scores, Cancer Sample Compared with Other Studies

	<i>Intrusion</i>		<i>Avoidance</i>		<i>Hyper-arousal</i>		<i>IES-R</i>		<i>IES</i>	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Cancer (N= 16)	6.42	5.28	7.75	4.29	3.87	4.31	18.05	12.10	14.17	8.42
1 Military Personnel working as rescuers at an earthquake	9.0	6.8	9.6	7.1	9.1	7.3	27.7	19.8		
2 Military Personnel (non-rescuers at an earthquake)	3.4	2.5	3.8	2.7	3.31	2.6	10.4	7.3		
3 Witnesses of Bloody Sunday	10.88	2.55	8.41	3.47	7.24	4.04	26.53	8.54	19.29	5.07
4 Pregnant Women involved in a Natural Disaster	5.7	5.4	3.9	5.2	2.3	3.6				
5 Patients with sudden Cardiac Event	4.0	6.1	3.9	6.7	4.2	5.2				
6 Breast Cancer: Recent Diagnosis	11.4	7.6	12.9	8.6					24.2	14.4
7 Breast Cancer: Diagnosed between 6 months and 5 years	7.4	9.1	9.0	10.6					16.4	18.0
8 Physical Trauma	14.9	7.7	9.6	6.7						
9 Informed of Huntington's Disease Risk	12.6	8.9	13.6	7.9						
10 Accidental Injury	5.5	6.0	9.3	8.5						
11. Cancer Survivors Average time since diagnosis 10.6 years	0.7	1.8	1.6	3.0	2.0	2.5				

Cetin, Rose, Ebrinc, Yigit, Elhai, Basoqlu (2005); 2. Cetin et al., 2005; 3. (Brunet, St-Hilaire, Jehel, King 2003) 5. Baumert, Simon, Gundel, Schmitt, Ladwig (2004); 6. Koopman et al., (2002) 7. (Cordova et al., 1995); 8. (Fernstein & Doleny, 1991); 9. (Horowitz, Field, Zanko, Donnelly, Epstein, Longo(2001); 11. Accidental Injury (Malt, 1988), 12. Deimling, Kahana, Bowman, Schaefer (2002).

3.5.2.1 Hypothesis 1

Mean scores for the total IES and IES-R scales will be elevated at levels comparable with other samples exposed to a traumatic event.

Considerably more published data were available for the IES as compared with the newer IES-R measure. Similarly, more data pertaining to subscales were presented in published studies, including Horowitz and Sundin's (2003) review.

IES and IES-R total scores

When comparing total IES-R scores, the cancer sample had higher total scores only as compared to the military personnel control group sample (Mean difference = 7.65, $d = .78$). IES scores were lower than most samples for which data were available but were comparable with Cordova et al.'s (1995) breast cancer sample (Mean difference = 2.23, $d = .16$).

IES-R subscales

The cancer patients had higher mean scores on several of the subscales, as compared with other samples. Thus mean differences and effect sizes were calculated. The results were as follows. The current cancer sample had higher scores on the intrusion subscale as compared with military personnel (Mean difference = 3.02, $d = .77$); sudden myocardial infarction, (Mean difference = 2.42, $d = .42$); accidental injury (Mean difference = .92, $d = .16$) natural disaster (Mean difference = .72, $d = .13$) and cancer survivors (Mean difference = 5.72, $d = 1.61$).

Similarly, the cancer participants reported higher scores than 3 samples on the avoidance subscale. Cancer patients had higher scores than the military personnel (Mean difference = 2.95, $d = 1.16$); natural disaster (Mean difference = 2.85, $d = .81$); cardiac event (Mean difference = 3.85, $d = .70$) and cancer survivors (Mean difference = 6.15, $d = 1.7$).

The cancer patients also had higher mean scores on the hyper-arousal scale than the military personnel (Mean difference = .56, $d = 16$); pregnant women involved in a natural disaster (Mean difference = 1.57, $d = .39$) and the cancer survivors (Mean difference = 1.87, $d = .55$).

3.5.2.2 Hypothesis 2

IES-R scores will be negatively correlated with quality of life scores

A complete table of correlations is provided in Appendix E. Scores on the IES-R ($r = -.66$, $p < .01$) and the IES ($r = -.56$, $p < .05$) were negatively correlated with FACT-G total scores. Similarly, scores on the hyper-arousal ($r = -.77$, $p < .01$) and intrusions ($r = -.60$, $p < .05$) subscales were negatively correlated with FACT-G total scores. Scores on the avoidance subscale were not associated with FACT-G scores.

The DASS stress ($r = .66$, $p < .01$) and anxiety ($r = .59$, $p < .05$) subscales were significantly correlated with the intrusions subscale. Stress ($r = .82$, $p < .01$) and anxiety ($r = .71$, $p < .01$) were significantly associated with the hyper-arousal subscale.

The depression subscale, however, was not correlated with the IES, or IES-R total scores, or the avoidance or intrusion subscales. However, the depression subscale was correlated with scores on the hyper-arousal subscale ($r = .64$, $p < .01$) and IES-R total scores ($r = .53$, $p < .05$).

3.5.2.3 Hypothesis 3

IES-R subscales will be better predictors of quality of life scores as compared with the DASS scales.

To determine the extent of contribution of distress measures (e.g., IES-R subscales and DASS subscales) two multiple regressions were performed. The multiple regressions for each of the

distress measures were conducted separately due to the multicollinearity of the DASS subscales with the IES-R subscales.

In the first multiple regression, using the stepwise procedure on SPSS, time since diagnosis was entered at the first step. As shown in Table 9, R square change was significant and time since diagnosis (Beta = -.71, $p < .05$) accounted for 51% of the variance on quality of life scores. Adding, IES-R hyper-arousal (Beta = -.62, $p < .01$) to the model added a further 35% of variance on FACT-G scores. At the third and fourth steps, neither intrusions, nor avoidance added significant amounts of variance to the model.

TABLE 9
Stepwise Multiple Regression IES-R Subscales Regressed on Dependent Variable, Quality of Life

<i>Model</i>	<i>R</i>	<i>R square</i>	<i>Adjusted R Square</i>	<i>Std. Error of the Estimate</i>	<i>R Square Change</i>	<i>F Change</i>	<i>df1</i>	<i>df2</i>	<i>Sig. F Change</i>
1	.718 ^a	.516	.481	8.28026	.516	14.906	1	14	.002
2	.931 ^b	.867	.846	4.50482	.351	34.300	1	13	.000
3	.933 ^c	.870	.838	4.62861	.003	.314	1	12	.586
4	.935 ^d	.874	.828	4.76208	.004	.337	1	11	.573

Multiple R = .93, Adjusted R = .87, F = 19.01 (4,11), $p < .01$.

In the second multiple regression, again using the stepwise procedure and entering time-since diagnosis at the first step (Beta = -.71, $p < .05$), stress, depression and anxiety were entered at the second, third and final steps. As shown in Table 10, the stress (Beta = -.53, $p < .01$) subscale added a further 26% of variance on quality of life scores, but neither anxiety nor depression contributed any further variance.

TABLE 10
Stepwise Multiple Regression DASS scales Regressed on Dependent Variable, Quality of Life.

<i>Model</i>	<i>R</i>	<i>R Square</i>	<i>Adjusted R Square</i>	<i>Std. Error of the Estimate</i>	<i>R Square Change</i>	<i>F Change</i>	<i>df1</i>	<i>df2</i>	<i>Sig. F Change</i>
1	.718 ^a	.516	.481	8.28026	.516	14.906	1	14	.002
2	.882 ^b	.777	.743	5.82712	.262	15.269	1	13	.002
3	.882 ^c	.778	.722	6.05939	.000	.022	1	12	.883
4	.887 ^d	.787	.710	6.19347	.009	.486	1	11	.500

Multiple R = .88, Adjusted R = .78, F=10.16 (4,11), p < .01.

3.6 Discussion

3.6.1 Overview of Results

The analyses in this chapter focused on measuring distress using the IES and IES-R. In terms of the hypotheses proposed in the introduction to this chapter, support was found for two of the three hypotheses proposed. Hypothesis 1 was not supported. The cancer sample reported lower mean scores on the IES-R and IES scales when compared with other traumatic groups. In support of Hypothesis 2, IES and IES-R total scores and subscale scores were correlated with FACT-G total scores. Intrusions and hyper-arousal subscale scores, but not avoidance scores, were strongly correlated with FACT-G total scores. In support of Hypothesis 3, the results indicated that the IES-R explained more variance on FACT-G scores, than did the DASS subscales.

3.6.2 Cancer: A Traumatic Event?

Some commentators argue that the nature of the trauma experienced in cancer is conceptually different than that of other traumatic events (Green et al. 1997). Limited data reporting on full scale scores on the IES and the IES-R were reported in the studies used for comparison.

When data were published, participants reported lower total scores than samples exposed to a range of traumatic events. However, they reported higher mean subscale scores when compared to a range of traumatic events including: pregnant women exposed to a natural disaster (Brunet et al. 2003), individuals experiencing a myocardial event (Baumert et al. 2004), individuals exposed to accidental injury (Malt, 1988) and cancer survivors (Deimling, 2002). Therefore, some support that the diagnosis and or experience of cancer, incorporating treatment, is conceptually similar to other traumatic events was found in this study.

3.6.3 Severity and Time Since Diagnosis

According to published severity ranges (Horowitz, 1982), the majority of participants scored in the low range. Patients with higher symptom scores tended to have received their diagnosis more than 4 years ago; had received a diagnosis of recurrence; and/or, had diagnoses such as head and neck or lung cancer. Previous research suggests that generally less stress is observed the longer the time that has elapsed since diagnosis (McBride et al., 2000). In this study, time since diagnosis was not directly related to IES or IES-R scores. Although as noted, several of the patients who reported higher scores received their diagnosis more than 4 years ago. Furthermore, patients reported more traumatic stress symptoms as compared with a cancer survivor sample (Deimling, 2002).

Participants in Deimling's (2002) study had a mean time since diagnosis of approximately 8 years. For example, the patients in this sample were on average 4 years since diagnosis. The level of symptoms reported in this sample was comparable to Cordova et al.'s (1995) breast cancer sample. The time since diagnosis in Cordova et al.'s (1995) ranged from 6 months to 5 years.

Generally, research suggests that distress experienced as a result of being exposed to a traumatic event decreases over time. McBride et al. (2000) note that this finding is not always applicable. Distress can continue for extended periods of time when the type of cancer results

in changes in physical appearance or sexual functioning. This view is also consistent with Segerstrom and Miller's (2004) account when they suggest that changes in identity are associated with increased distress. In two of the head and neck patients, considerable disfiguration was observed by the researcher; one patient no longer had the ability to eat or drink by mouth and had impaired speech. In other words, living with the reminder of the disfigurement and limitations such as the ability to speak/communicate and eat by mouth may suggest that these patients are subjected to stress as a result of changes in their identity.

3.6.4 Chronic versus Acute Stress?

Determining the nature of stress (i.e. acute versus chronic) experienced by cancer patients is complex. For example, McBride et al. (2000) who suggest that increased traumatic stress symptoms occur as a result of changes in identity suggest that the nature of stress experienced by cancer patients is 'acute'. In contrast, Segerstrom and Miller (2004) suggest that changes in identity are associated with chronic stress. In Dhabhar and McEwen's (1997, 2001) physiological theory of stress, they suggest that differential physiological responses occur in an adaptive manner depending on whether the stressor is experienced on a chronic (i.e. long term) or an acute (i.e., limited duration) basis.

It is possible that cancer patients experience both acute and chronic stress. An alternative hypothesis is that cancer patients experience acute stress for extended periods. For some patients, rather than being exposed to acute stress in the sense of a limited duration, they may be exposed to acute stress on a continuing (i.e. chronic) basis. Of those patients that showed more acute stress symptoms, some had received a diagnosis of recurrence. Patients who experience a diagnosis of recurrence may continue to experience acute stress due to ongoing threats to their life. For example, Koopman et al., (2002) suggests that the impact of cancer may be more extreme as compared with other traumatic events because not only is stress experienced at the time of diagnosis but stress may occur at other stages due to ongoing threats (i.e. either perceived or real) to life. Depending on the extent to which individuals

appraise ongoing threats to their life, they may experience acute stress reactions on a long term basis (i.e. chronic basis). According to Dhabhar and McEwen's (1997, 2001) physiological theory of stress, such a response would not be adaptive as such a response is designed to protect individuals in the short term only.

3.6.5 Overlap DASS and IES-R scales

The results also provide some support for Tjemsland et al.'s (1996) suggestion that measures of stress may be more suitable when attempting to measure the impact of cancer, rather than measures of emotion such as depression. For example, when predicting quality of life scores the stress scales of the DASS and the IES-R (i.e. hyper-arousal and stress), as compared with the other scales explained the most variance.

Nevertheless, considerable overlap existed between the DASS subscale measures and the IES-R subscales. In particular, and as would be expected, the DASS anxiety subscale and the hyper-arousal subscale were significantly correlated. Items in the anxiety subscale measure levels of autonomic arousal. As noted in the method section of Chapter 2, items reflect autonomic arousal and measure responses to questions such "I perspired noticeably (e.g., hands sweaty) in the absence of high temperatures or physical exertion". Such items would be expected to correlate with hyper-arousal. Similarly, the correlation between the stress measure and the hyper-arousal scale would be expected. For example, the DASS is designed to measure non-specific arousal such as having difficulty relaxing.

The DASS depression scale was also associated with the hyper-arousal scale. The depression items are designed to tap symptoms that are relevant to a DSM-IV-TR (APA, 2000) diagnosis of depression. For example, the items reflect criteria listed in the DSM-IV-TR (APA, 2000) manual such as hopelessness and/or a lack of interest/involvement in activities. In this sample, as was reported in Chapter 2, the cancer patients reported considerably lower levels of depression as compared with the University sample. Thus, the relationship observed

between the DASS depression and hyper-arousal subscales is difficult to interpret and could be due to the similarity in items particularly those items that emphasise difficulties sleeping. For instance, in depression, a common symptom is changing sleep patterns (either decreased or increased).

Nevertheless, the relationships between the hyper-arousal and depression scale could be explained by either a chronic or acute account of stress. For instance, according to Selye's (1976) general adaptation theory of stress, continued exposure to chronic stress results in a continual activation of the sympathetic nervous system, eventually leading to a state of exhaustion. Seligman's (1974) learned helplessness theory predicts, for example, that with continued exposure to an uncontrollable stressor, an individual will eventually give up (i.e. become hopeless) and depressed.

Unfortunately, it is difficult to disentangle the effects of the disease and/or the treatment versus those occurring due the psychosocial aspects of the illness experience. For instance, in depression, a common symptom is fatigue, however, this may be associated with the disease (i.e. cancer) or the treatment, or physical changes that occur following certain kinds of treatment (e.g., anemia). Similarly, the effects of stress associated with perceptions of ongoing threats to life could be responsible for the onset and/or expression of depression.

Baumert et al., (2004) reports only limited support for the content validity of the hyper-arousal subscale of the IES-R, suggesting that the scale did not adequately discriminate between individuals with exaggerated startle reactions. The presence of this symptom is included in the DSM-IV criteria. Indeed, a lack of validation may be why there are limited data available for comparison with respect to the hyper-arousal subscale. Although, peripheral to the specific aims of this thesis, future research that assesses the validity of the hyper-arousal subscale using psycho-physiological measures appears necessary to understand

fully the nature of distress experienced by cancer patients and its relationship with reduced quality of life.

3.6.6 Limitations

There are some limitations that apply to the results reported and conclusions drawn in this study. First, researchers using the IES and IES-R propose that the existence of some symptoms (i.e. a score greater than 0) indicates the presence of distress occurring as a result of 'acute stress'. This interpretation is somewhat flawed because elevated symptoms on the IES subscales have been reported in general populations that supposedly have not been exposed to traumatic events (Briere, 1997). Indeed elevated scores were observed in the military personnel control group. Admittedly though this group may not be the ideal type of control group as they may be exposed to other traumatic events during the course of their work. Furthermore, Horowitz (1982) and Tjemsland et al., (1996) provide a basis for categorising severity scores, however, the extent to which these severity scores are valid is not known.

In addition, specific limitations apply to this study. For example, the results are based on a small sample size and thus the results may not be generalised to the wider population of cancer patients. Due to a lack of power, some relationships that potentially exist among study variables may have been obscured.

3.6.7 Conclusion

Results confirmed the presence of acute stress symptoms as measured by the IES-R and its subscales pertaining to avoidance, intrusions and in particular, hyper-arousal. Patients showed low to moderate levels of symptoms, however, participants' symptoms were higher than other studies involving cancer survivors and were comparable to other studies involving individuals exposed to traumatic events. Thus, based on the findings reviewed it appears that the IES-R, which provides a measure of acute stress, may provide a more valid and reliable

measure of distress in cancer samples as compared with measures of chronic distress such as the DASS.

4 CANCER: THE ROLE OF EMOTION INHIBITION IN RESEARCH AND THERAPEUTIC APPROACHES

4.1.1 Emotion Focused Therapeutic Approaches

The concept of emotional inhibition has been studied extensively in cancer populations and has long been implicated as a potential risk factor in the onset of cancer and/or the recurrence of cancer (Garssen, 2004; Giese-Davis & Spiegel, 2003; McKenna, Zevon, Corn & Rounds, 1999). The construct of emotional inhibition is also central to emotion focused therapeutic approaches. Over the past two decades, many commentators have suggested that therapies based on the expression of emotion are the most efficacious in cancer samples (Kemeny & Miller, 2003). Two main approaches are cited in the literature and include Supportive Expressive Group Therapy (SEGT; Spiegel, 2002; Spiegel, Bloom, Kraemer & Gottheil, 1989; Spiegel & Bloom, 1983; Spiegel, Bloom & Yalom, 1981) and Pennebaker's (1997; Pennebaker & Beall, 1986) emotional disclosure method. Emotion focused therapeutic approaches claim to draw their theoretical basis from research that links the inhibition of emotion with psychological distress (Spiegel & Giese-Davis, 2003; Pennebaker, 1997, 1989; Pennebaker & Beall, 1986).

Supportive expressive group therapy/written disclosure and the inhibition hypothesis

The SEGT program was conceived by Spiegel and colleagues at Stanford University (Spiegel, 2002; Spiegel et al. 1989; Spiegel & Bloom, 1983; Spiegel et al., 1981). Current accounts of the SEGT program describe it as an approach focused on the facilitation and expression of emotional states such as fear, anger and sadness with respect to a range of issues, including existential issues such as death and dying (Classen et al., 2001; Giese-Davis, Piemme, Dillon, Wilson, 2006). The second approach, also based on the notion that the inhibition of emotion results in adverse health outcomes, involves encouraging individuals to express emotion via either writing or verbal disclosure.

In essence, researchers adopting the ‘inhibition’ hypothesis propose that individuals who inhibit emotion, particularly negative emotion, exhibit high levels of distress, however, they are in denial of this distress. Pennebaker (1997, p. 164) highlights the role of the central nervous system when referring to the inhibition hypothesis and proposes that this over activation could result in a chronic (i.e, ‘long term’) stressor.

The original theory that motivated the first studies on writing was based on the assumption that not talking about important psychological phenomena is a form of inhibition. Drawing on the animal and psychophysiological literatures, we posited that active inhibition is a form of psychological work. This inhibitory work, which is reflected in autonomic and central nervous system activity, could be viewed as a long-term low level stressor.

Pennebaker, 1997, p. 164

4.1.2 Critique of Emotion-Focused Approaches

Over the past 20 years, the Stanford group has consistently demonstrated the efficacy of SEGT in reducing depression and anxiety symptoms (Spiegel et al, 1981); maladaptive coping responses (Spiegel et al. 1981); perceptions of pain (Spiegel & Bloom, 1983); and, trauma symptoms (Classen et al., 2001). Crucial to current explanations concerning SEGT is that the expression of emotion, particularly negative emotion is therapeutic. It is important to note that SEGT program was conceived as a group support program (Spiegel et al. 1981; Spiegel & Bloom, 1983). According to Giese-Davis and Spiegel (2003), it came as a complete surprise to those involved in these early sessions when it was found that patients participating in SEGT sessions for 12 months were less depressed and anxious when compared to a no-treatment group (see Spiegel et al., 1981). Furthermore, when death certificates were followed up 10 years later, it was found that patients who had participated in SEGT lived on average 18 months longer than patients who had received standard care (Spiegel et al. 1989). Commentary describing the content and process of these early sessions

is limited. Nevertheless, it appears that all group sessions were led by a professional therapist who provided guidance to group members with respect to a range of issues. Patients were encouraged to share their concerns, fears, and experiences and a major emphasis was placed on group members' modelling of coping strategies. In addition, explicit teaching and practice in self-hypnosis for pain control was a main component in these sessions (Spiegel & Bloom, 1983).

Survival claim controversial

The increased 'survival' claim remains controversial (for a review see Fox, 1998; Palmer & Coyne, 2004). According to Spiegel and Giese-Davis (2003) four studies have replicated a survival advantage (e.g., Fawzy, Fawzy, Hyun, Elasoff, Guthrie, Fahery & Morton, 1993, Richardson, Shelton., Krailo, & Levine, 1990; Kuchler, Henne-Bruns, Rappat, Graul, Holst, Williams, et al, 1999; McCorkle, Strumpf, Nuamah, Adler, Cooley, Jepson et al. 2000).

While some dispute the effect, others dispute that that the effect can be attributed to specific foci, or components of the intervention (Palmer & Coyne, 2004). Indeed, this criticism is warranted. As argued by Palmer and Coyne (2004), the extent to which the process of psychotherapy is present in those studies cited in support of the 'survival' claim is dubious. For instance, the Richardson et al. (1990) study was essentially a program aimed at providing education to improve adherence to medication. Further, in other studies none have exclusively focused on the expression of emotion. For example in Fawzy et al's (1993) study participants received health education, stress management (including relaxation) general coping and group support.

A recent study involving 235 women with metastatic breast cancer, who were randomly assigned to a manualised version of the SEGT approach or a no treatment control group, failed to replicate the survival finding (Goodwin, Leszcz, Ennis, Koopmans, Vincent, Guther

et al, 2001). However, improvements in mood were observed in patients who exhibited high levels distress at the commencement of the trial.

Multi-modal approach precludes assessment of the mechanism responsible for therapeutic change

While many studies provide support for the efficacy of SET, particularly in terms of improving mood, the multi-modal nature of this intervention precludes definitive assessment of the precise psychological mechanism(s) responsible for therapeutic change. Current studies may achieve their effects due to the group support, and have little to do with the expression of negative emotional states. Earlier studies may have been efficacious due to hypnosis for pain control. Alternatively, important therapeutic ingredients might comprise a combination of factors (e.g., group support and emotional expression). According to Telch and Telch (1985, p. 321), a major criticism of studies evaluating the efficacy of the SEGT approach is that “hardly any have isolated the active therapeutic components”.

Inhibition and SEGT?

Indeed, it is not known to what extent the ‘inhibition’ hypothesis shaped the development of the SEGT, particularly initially. Rather it appears that theoretical rationales have been developed in a retrospective manner. For instance, during the 1980s commentators suggested that the main therapeutic ingredients responsible for change included “catharsis, a sense of community with others experiencing the same situation, and feelings of altruism and worth that accompany giving and receiving support” (Telch & Telch, 1985, p.330). During the 1990s the focus shifted slightly and researchers suggested that: “participants [were] encouraged to confront their problems, strengthen their relationships and find enhanced meaning in their lives” (Classen et al., 2001, p.495). More recently, commentary suggests that: “[d]irect processing of group members’ deaths intensifies emotional experiences, allowing participants to practice and gain skill at tolerating negative affect in the moment” (Giese-Davis, Koopman, Butler, Classen, Cordova, Fobair et al., 2002, p. 917).

Written disclosure a more direct method to promote the expression of emotion

In contrast to the SEGT approach, Pennebaker's (1997; Pennebaker & Beal, 1986) emotional disclosure method appears to incorporate the notion of emotional expression as the central and isolated therapeutic ingredient. In a traditional experimental application of Pennebaker's (1997) written disclosure paradigm, participants are randomly allocated to either the experimental group (Emotional Writing Group) or the control group (Trivial Writing Group). Participants in the Emotional Writing Group write about their very deepest thoughts and feelings about the most traumatic experience of their life for 4 days for 15 minutes per day. Control participants write for the same amount of time, and number of sessions, on a trivial topic such as describing the contents of their closets.

This method has been applied across a variety of settings (for reviews see: Frisina, Brood & Lepore, 2004; Pennebaker & Chung, 2007; Sloan & Marx, 2004,; Smyth, 1999). Since its inception in the '80s, 150 studies have assessed its efficacy (Pennebaker & Chung, 2006). A substantive literature supports the hypothesis that emotional disclosure (either by written or verbal methods) of upsetting/traumatic experiences results in improvements in physical and psychological health (Smyth, 1999; Sloan & Marx 2004). In a meta-analysis involving 13 written disclosure studies, Smyth (1999) reports a weighted mean effect size of $d = .47$, indicative of a moderate effect size.

Sloan and Marx (2004) suggest that the expressive writing paradigm has now been tested across a wide variety of domains, including job loss (Spera, Buhrfeind, & Pennebaker, 1994); asthma diagnosis (Smyth, Stone, Hurewitz, & Kaell, 1999); cancer diagnosis (de Moor, Sterner, Hall, Warneke, Gilani, Amato et al. 2002); bereavement (Stroebe, Strobe, Schut, Zech, & Bout, 2002); and, traumatic experiences (Batten, Follette, Hall, & Palm, 2002). Furthermore, Klein and Boals (2001) report reductions in intrusive thoughts and images and

Schoutrop, Lange, Hanewald, Davidovich and Salomon (2002) report reductions in avoidance symptoms.

Central to Pennebaker's (1997) approach is the notion that writing about one's most traumatic experience increases the likelihood that any emotional material that has been inhibited (but still causing distress) will be brought into consciousness, written about, and subsequently, lead to reductions in distress.

4.1.3 Inhibition: Traditional Research Focus

Whilst there is considerable research that assesses the efficacy of therapies that derive their basis on the notion of inhibition, traditionally the role of inhibition has been studied with reference to predicting the onset and/or recurrence of cancer (for reviews see: Garssen, 2004; Giese-Davis & Spiegel, 2003; Kiecolt-Glaser McQuire, Robles, Walker, 2002; McKenna, et al., 1999). For instance, Garssen (2004), in a critical review of literature spanning 30 years, concluded that of all the psychosocial variables studied in relation to cancer onset and/or progression, repression of negative emotions (i.e., inhibition) appears to show the most 'promise'. However, there remain a number of difficulties in terms of assessing this literature.

Synthesis of literature difficult due to the range of concepts used to describe inhibition

Synthesis of the literature assessing the role of inhibition in the initiation and progression of cancer is difficult due to the number of different ways concepts related to the 'inhibition of emotion' are described and measured. Giese-Davis and Spiegel (2001) note that varieties of terms are used to describe the concept of inhibition such as suppression, repression of affect, compliance, unassertiveness, and denial. Complicating matters further, many researchers embed the inhibition concept (and its various derivatives) within models that describe particular personality styles (e.g., Type C Personality; Temoshok and Fox, 1984).

Moreover, it is usually unclear which aspects, and to what extent, different components of these coping styles and or emotional regulatory strategies impact on the observed findings. For instance, the degree of conceptual overlap (or independence) that exists among the various measures remains unexplored. In the small number of prospective studies available for review, researchers do not always include all (and indeed, some do not include any) aspects of the prescribed coping models or personality styles. For example, Sabbioni (1991) describes the typical characteristics that comprise the Type C Personality Style.

Characteristics of this so-called cancer prone personality (Morris, 1980) include being overly appeasing and patient; compliant and unassertive; seeking harmony; defensive in response to stress; and unexpressive of emotional reactions, particularly anger.

A closer examination of the prospective studies that claim to be assessing the role of Type C personality (see Sabbioni, 1991) reveals that the characteristics measured include excessive self-esteem, hysterical disposition and unresolved recent grief (see Jasmin, Le, Marty, Herzberg, 1990). As noted by Sabbioni (1991, p.9) these characteristic “could be comparable with the concept of a Type C personality”. Obviously, without appropriate analysis one does not know whether these concepts are related at all. In contrast, other studies assess only a limited number of the proposed Type C characteristics such as levels of conformity and suppression (e.g., see Greer & Watson, 1985; Temoshok and Fox, 1984).

Inconsistencies in literature preclude assessment of the utility of measures when predicting adjustment/survival outcomes

Another dominant view in the cancer literature is that particular coping styles such as ‘Fighting Spirit’ (Greer et al., 1979) predict survival from cancer. Reviews conducted in this area are unable to provide definitive answers due to a large number of inconsistencies in findings reported in the literature (for reviews see: Fox, 1998, Garsson, 2004). As noted by Garsson (2004), of 70 studies that explored the role of psychosocial factors in the onset and/or progression of cancer, 70% showed an association; however, within each of these studies the

effects across studies were not replicated. For example, Type C personality is reported to be associated with death from cancer (Greer & Watson, 1985; Temoshok & Fox, 1984); and similarly, the possession of a “fighting spirit” following breast surgery has been associated with recurrence-free survival (Greer et al. 1979). In contrast, other studies have found that the risk of relapse was predicted by greater levels of hopelessness/helplessness but was unrelated to the construct of “fighting spirit” (Watson, Haviland, Greer, Davidson, Bliss, 1999).

The majority of studies that report on the relationship between cancer coping styles/regulatory strategies and the onset of cancer involve retrospective accounts so it is impossible to know whether a coping style described as say “helpless/hopeless” is a cause or a consequence of getting cancer. Depressed patients are likely to recall more negative events (Moffit, Singer, Nelligan, Carson & Vyse, 1994). As noted by Garssen (2004), the failure to include multiple measures and/or to assess their interactive effects (and possibly additive effects) limits our understandings concerning their influence on disease onset and/or progression.

A lack of understanding concerning whether emotional inhibition trait or state based

A further criticism of most studies is that researchers include only a single (i.e., one time) measure of these constructs (Giese-Davis & Spiegel, 2001). In other words, it is not possible to determine whether these coping styles are trait based and are therefore chronic in style (i.e. lead to the onset of cancer) or whether indeed they are state based (i.e. occur as a result of receiving a cancer diagnosis). There is some tentative evidence that maladaptive coping styles such as hopelessness/helplessness are amenable to change via psychosocial intervention (see: Watson, et al. 1999). Yet, without collecting multiple measures of the constructs (e.g., pre and post intervention) and without analysis to determine the degree of overlap among the various coping and inhibition constructs, the extent to which these coping strategies are amenable to change via psychosocial intervention is unclear. For instance, a failure to assess these at multiple data collection points precludes assessment of the stability (i.e., state versus

trait) of these constructs. Despite the best efforts of clinicians, the potential for some coping/personality styles to change following psychosocial intervention may be limited.

Emotion Regulation: Incorporating measures of expression as well as inhibition

Giese-Davis et al., (2002) suggest that without the inclusion of outcome measures relevant to emotional inhibition on the one hand, and emotional expression on the other, the extent of change in the regulation of emotion (i.e. from inhibition to expression) cannot be determined. Furthermore, Giese-Davis and Spiegel (2003) argue that many of the inconsistencies in the cancer literature with respect to the role of inhibition and particular coping styles, might be resolved by considering the phase at which a patient is with respect to their diagnosis and the extent to which they demonstrate flexibility in their coping style. For instance, they suggest that:

... depression at diagnosis is normal and denial of depression at this time (repression) is a risk factor associated with shorter survival ... The ability to change, to move from a genuine distress at diagnosis to lower distress over time, is a protective factor associated with longer survival” .

Giese-Davis & Spiegel, 2003, p. 1054

Distinguishing among inhibition concepts: suppression versus repression

Recent research examining the efficacy of the SEGT approach has attempted to be more precise regarding the psychological mechanisms involved in therapeutic change by measuring actual changes in emotional inhibition by including measures that assess constructs such as the tendency to suppress and/or repress negative emotions. Furthermore, Giese-Davis and Spiegel (2003, p. 1053) offer a coping skills framework for understanding the role of emotional inhibition on the one hand and emotional expression on the other by utilising the concepts of flexibility and affect, or emotional regulation.

For example:

... the ability to resolve depression demonstrates a flexible affect regulation system and coping skills. Likewise repressive-defensiveness is a rigid style that does not enable the working through of intense and changeable emotion.

Giese-Davis & Spiegel, 2003, p. 1053

According to Giese-Davis and Spiegel (2001, p. 419) suppression (defined as “intentionally avoids thinking about disturbing problems, desires, feelings, or experiences”) is less likely to be a pervasive or chronic coping strategy. In contrast, the tendency to use repression (defined “as a defence mechanism in which the person is unable to recall or be cognitively aware of disturbing wishes, feelings, thoughts, or experiences”) is more likely to be a chronic style of affect regulation and therefore is unlikely to be amenable to change following intervention.

4.1.4 Linking relevant theory concerning emotion and coping

Emotion theorists, Diamond and Aspinwall (2003) suggest that studies of emotional regulation in adult populations would benefit from integrating theory regarding self-regulation and emotion regulation. Such approaches have been used in studies investigating the development of emotional regulation strategies of children. However, they argue that such an approach is absent from the adult literature. They suggest that this is inappropriate especially given that “[i]ndividual differences in capacities and strategies for emotion regulation carry over into adulthood where they influence coping styles, problem solving, social support processes, relationship quality and mental and physical health” (Diamond & Aspinall, 2003, p. 126).

Diamond and Aspinwall (2003) endorse the work of Carver and Scheier (1990) who distinguish emotion regulation from self-regulation, as follows:

Whereas emotion regulation involves the modulation of emotion-related experiences through internal and transactional processes, self-regulation is typically conceptualized as involving the control, direction, and correction of one's own actions in the process of moving toward or away from various goals (Diamond & Aspinwall, 2003, p. 133).

Diamond and Aspinwall (2003) argue for the centrality of emotional experiences with respect to self-regulatory behaviour. For example, they cite Siegel (1999, p.245, cited in, Diamond & Aspinwall, 2003) who propose that emotion regulation "... can be seen at the centre of the self-organization of the mind" and Dodge (1991, p. 159) who notes that "... emotion is the energy that drives, organizes, amplifies, and attenuates cognitive activity and in turn is the experience and expression of this activity."

Diamond and Aspinwall (2003) further argue that in the adult coping literature, affect and cognition have been viewed as opposing process (e.g., thinking vs feeling, emotion focus vs. problem focused coping) with emotions conceived as having a disruptive function on cognition and behaviour. They discuss the well known work of Lazarus and Folkman (1984) and suggest that while these researchers did not initially conceive as one regulatory approach (e.g., problem-focused coping) as superior to the other (e.g, emotion-focused coping), subsequent research has described emotional focused strategies towards coping as maladaptive. Indeed many studies report the association between emotion-focused coping strategies with adverse health outcomes (Lazarus & Folkman, 1984).

Nevertheless, Diamond and Aspinwall (2003) suggest that research that documents the positive effects of emotion regulation strategies on well-being are ignored in literature on coping in adult populations. They outline some potential 'adaptive' functions that emotional processing and expression may serve in adult coping:

- a) direct one's attention toward central concerns;
- b) result in the identification of discrepancies between one's progress and the expected rate of progress;
- c) result in habituation to the stressor through repeated exposure or through cognitive reappraisal;
- d) facilitate regulation of the social environment (e.g., by letting other people know of one's situation) and;
- e) aid in the selection of satisfying emotional environments (Diamond & Aspinall, 2003, p. 135).

Stanton, Kirk, Cameron and Danouff-Burg (2002) incorporate self-regulatory theory, along with functional approaches to the understanding of emotion, into the development of a measure that assesses emotional expression and processing. They also argue that previous coping measures that attempt to measure emotional coping, as described by Lazarus and Folkman (1984), are confounded because researchers include items that measure distress (not emotional expression). Thus, they argue that it is not surprising that correlations reporting associations with distress are plentiful in the stress and coping literature. In contrast, the Stanton et al. (2002) measure is based on functional approaches that see the role of emotion and expression as adaptive and thus their measure has been designed to tap constructs reflecting the processing and expression of emotions and not distress.

Emotion approach coping is still defined in terms of Lazarus and Folkman's (1984) description of coping processes in that emotion approach coping is presumed to involve "effortful attempts to approach one's emotions in response to situations appraised as taxing or exceeding one's resources (Stanton et al., 2002, p. 1151). Furthermore, Stanton et al. (2002) suggest that while individuals may develop characteristic, and perhaps stable ways of coping across the lifespan, these can change as a result of a number of external factors (e.g., perhaps

intervention). The measure captures 3 aspects relating to emotional regulation, including: i) emotion identification (e.g., self-awareness of one's emotional states) ii) emotional processing (effortful attempts at exploring and understanding one's own emotions iii) emotional expression (inclusive of both intrapersonal and interpersonal forms). Validation of this measure occurred over 4 studies (see Stanton et al. 2002). Importantly, baseline levels of emotional expression and processing predicted increased hopefulness and instrumentality and decreased symptoms of anxiety and depression (Stanton et al., 2002).

4.2 Summary and Aims

As reviewed, the construct of inhibition has been extensively studied and forms the basis of the major therapeutic approaches used to decrease distress. Incorporating self-regulatory theory by including a new measure of emotional approach coping may provide insight into the extent that cancer patients engage in emotional processing and expression. However, there remain several inconsistencies in the literature pertaining to the emotional inhibition construct and some of these may occur due to the nature of the measures used. For example, to date the extent of similarity among measures of inhibition remains relatively unexplored. Before proceeding to the design and implementation of an intervention based on the expression emotion (see Chapter 8) the extent to which these constructs are overlapping would seem important in terms of deciding which measures may be sensitive to changes in the tendency to inhibit and/or express emotion. Thus, the major aim of this study was to identify to extent that the measures used to assess inhibition represent a single unidimensional construct.

Furthermore,

Furthermore, inconsistent results with respect to predicting outcomes such as distress and survival exist. Therefore, a further aim of the analyses presented in this chapter was to assess

the relationship between measures of emotion regulation (i.e. inhibition and expression) and outcomes including distress and quality of life.

In addition, the level of endorsement on items relevant to emotion regulation, personality (e.g., Type C personality) and cancer coping styles (e.g., the Mental Adjustment to Cancer Scale) will also be presented. Within this analysis, comparisons between males and females are performed. For instance, the majority of research involving therapeutic approaches such as the SEGT have focused on women with breast cancer. Thus, there may be important gender differences that have been overlooked in previous research. Males and females may differ in the extent to which they endorse particular coping styles and or emotional regulatory strategies.

Moreover, the extent to which the general population inhibits emotion has generally been unexplored. Thus, when normative data are available for both healthy and cancer groups, effect sizes will be calculated to assess the extent of difference between these groups. This comparison appears essential when determining whether the construct of inhibition is unique to illness populations as is advocated in the literature.

The main aims of this study are summarised as follows:

1. Describe the extent of endorsement of coping styles/personality styles and emotion regulatory strategies as compared with previous research involving healthy samples and cancer patient samples.
2. Explore whether endorsement of items differs between males and females.
3. Explore differences between normal and healthy groups using normative data.
4. Assess the extent to which measures of emotional inhibition, coping and personality style overlap.

5. Assess the extent to which coping styles and emotion regulatory measures (inhibition/expression) measures predict outcomes such as quality of life and distress.

4.3 Method

4.3.1 Participants

Thirteen participants with a history of cancer (e.g. time since diagnosis ranged from 6 months to 13 years, $SD = 43.53$) and three patients with a current diagnosis of cancer participated in this study. There were 11 females (Mean = 55.27, SD , 8.69) and 5 males (Mean = 59.40, SD , 9.65) who had previously received a diagnosis of cancer. A full account of the demographic and medical characteristics of participants was provided in Chapter 2.

4.3.2 Measures

Participants completed a range of questionnaires reflective of cancer coping styles, emotion regulation strategies, distress and quality of life.

Coping styles

The Mental Adjustment to Cancer (MAC; Watson, Greer, Young, Inavat, Burgess & Robertson, 1988) comprises 40 items and is designed to assess specific ways of responding to cancer. The scale has 5 subscales, including, Fighting Spirit, Helpless/Hopeless, Anxious Preoccupation, Fatalism, and Denial (i.e., Avoidance). Internal consistency of the subscales ranges from .65 (fatalism) to .84 (fighting spirit). Items include statements such as: “I have been doing things that I believe will improve my health, e.g. “changed my diet”; and “I believe that my positive attitude will benefit my health”. Items are scored on a Likert scale from 1, “Definitely does not apply to me” to 4 “Definitely applies to me”.

The Lifestyle Defence Mechanisms Inventory (LDMI; Spielberger and Reheiser, 2002) comprises 20 items that measure the extent to which patients may resort to using

psychological defences such as repression and denial to reduce the intensity of unacceptable and painful emotional states. It contains two subscales, Rational Emotive/Defensiveness (R/ED) and Need for Harmony (NH) and has typically been used by researchers interested in the Type C personality construct. Examples of statements include: “I try to do what is sensible and logical”; “When I am in a situation in which I strongly disagree with other people, I try not to show my emotions”. Items are scored on a Likert scale from 1 (‘almost never’) to 4 (‘almost always’).

Emotion regulation strategies: inhibition

The Courtauld Emotional Control Scale (CECS; Watson and Greer, 1983) measures the extent to which individuals report they control (i.e. suppress) specific emotions including anger, anxiety and depressed mood. The CECS contains 21 items questionnaire and has 3 subscales (i.e., anger, anxiety, depressed mood). Internal consistency alphas range from 0.86 (anger subscale) and to 0.88 (depressed mood and anxiety subscales). One month test-retest reliability for the total CECS is 0.95 (Watson and Greer, 1983).

The Weinberger Adjustment Inventory, Short Form (WAI; Weinberger, 1990) provides an assessment of the extent to which an individual represses affect; that is, it identifies individuals classically known as “Repressors” (Mulvaney, Kihlstrom, Figueredo & Schwartz, 1992). Turvey and Salovey (1993) suggest that the WAI is the most psychometrically sound of all measures designed to identify ‘repressors’. The short form scale contains 37 items. The ‘Distress’ subscale measures levels of negative affect and includes items reflective of states of anxiety, depression, self esteem and well-being. The ‘Restraint’ subscale measures an individual’s impulse or emotional control with respect to delaying emotional reactions such as hostility in preference for achieving longer term goals. It includes items that assess the suppression of aggression, impulse control, consideration of others, and responsibility. Cronbach’s alpha for the short form subscales range from 0.78 to 0.86, and 2 week test-retest

reliabilities reported are in the range of 0.75 to 0.88 (Brown, Tomarken, Orth, Loosen, Kalin & Davidson, 1996; Weinberger, 1990).

In this study, the purpose of using the inventory was to identify individuals who meet the criteria to be classified as a 'repressor'. According to Weinberger and Davidson (1994; Weinberger, 1990) 'repressors' are identified when the distress median score is lower than 27 and the restraint score is higher than 70. In this study, an effort to identify repressors on the basis of this criteria is made.

Emotional expression and emotional processing

The Emotional Approach Coping scale (EAC; Stanton et al., 2002) measures the extent to which individuals use emotional expression and emotional processing (i.e., emotional approach coping). The EAC is comprised of 16 items and includes 8 items that assess the extent to which individuals use emotional processing with statements such as: "I take the time to figure out what I'm really feeling" and "I explore my emotions." The other 8 items assess the extent to which an individual engages in emotional expression with statements such as: "I let my emotions come out freely", "I let my feelings come out." Items are scored on a Likert scale from 1, "I usually don't do this at all" to 4, "I usually do this a lot. Validation of the measure occurred over 4 studies (see Stanton et al., 2002) and involved a substantial sample (N = 400). Results reported by Stanton et al. (2002) demonstrate adequate scale consistency with alpha ranging from 0.88 to 0.90 across these studies. Four-week test-retest reliabilities (N= 223) with coefficients of 0.81 for emotional processing and 0.79 for emotional expression.

4.3.3 Procedure

Participants completed the questionnaire following attending an interview with the Researcher.

4.4 Results

4.4.1 Descriptive Statistics

All measures were assessed for missing data and the distribution of scores for each measure was checked for normality. Alpha coefficients were also calculated for each of the measures and subscales. These results, along with means and standard deviations for each of the measures, are presented according to the following 2 headings: Cancer Coping Styles and Emotion Regulation Strategies.

4.4.2 Cancer Coping Styles

The Mental Adjustment to Cancer scale (MAC; Watson et al., 1988)

Missing data on items comprising the MAC scale were minimal with just 3 items missing values. These values were replaced with the mean using the automated procedure on SPSS.

As shown in Table 11, scores on the ‘fighting spirit’ subscale were negatively skewed indicating that participants endorsed higher scores on this measure. In contrast, scores on the ‘avoidance’ subscale were positively skewed with participants endorsing low scores.

Low scores on this scale are essential and are in fact a prerequisite for checking the suitability of responses. Greer, Morrey and Watson (1988) suggest that if high scores are indicated on this variable then data may not be valid. For instance, the authors suggest that the measure does not purport to measure denial.

As shown in Table 11, the alpha coefficient for the ‘anxious preoccupation’ subscale is satisfactory but the alpha coefficients for all other subscales were considerably lower with the subscale, ‘fatalistic’ showing poor reliability.

TABLE 11**Descriptive Statistics: The Mental Adjustment to Cancer Scale**

	<i>Mean</i>	<i>SD</i>	<i>Min/Max</i> <i>observed</i>	<i>Min/Max</i> <i>possible</i>	<i>Skewness</i>	<i>SE</i> <i>Skewness</i>	<i>Kurtosis</i>	<i>SE</i> <i>Kurtosis</i>	<i>Alpha</i> <i>coefficient</i>
AP	21.81	5.31	13-29	16-64	.15	.56	-1.34	1.09	.76
HH	8.25	2.08	6-13	6-24	.58	.56	-0.98	1.09	.57
FS	53.07	4.30	44-60	9-36	-.25	.56	.64	1.09	.57
FA	15.06	3.43	9-23	8-32	.54	.56	1.01	1.09	.40
AV	1.43	.72	1-3	1-5	1.43	.56	.78	1.09	n/a

AP= Anxious Preoccupation; HH= Helpless/Hopeless; FS= Fighting Spirit; FA= Fatalistic ; AV= Avoidance

MAC: Gender differences

Shown in Table 12 are the mean scores, standard deviations, and t-test results for males (N = 5) versus females (N=11) on the MAC subscales. There were no significant mean differences between scores reported by males and females on any of the MAC subscales.

TABLE 12**MAC Coping Styles: T-tests Comparing Means for Females and Males**

		<i>Mean</i>	<i>SD</i>	<i>t</i>	<i>df</i>	<i>P</i>
Anxious Preoccupation	F	23.09	5.04			
	M	19.0	5.29	1.48	14	.161
Helpless/Hopeless	F	8.72	2.24			
	M	7.20	1.30	1.49	14	.182
Fighting Spirit	F	52.92	4.59			
	M	53.41	2.69	-.223	14	.827
Fatalistic	F	15.17	3.94			
	M	14.80	1.48	.210	14	.837
Avoidance	F	1.36	.64			
	M	1.6	.89	-.58	14	.565

MAC: Endorsement of coping styles: comparisons with normative data

As shown in Table 13, compared with reference data reported by Greer, Moorey and Watson, (1989) patients reported significantly higher scores on the fighting spirit subscale (Mean difference= 7.32 $d = 1.15$) and lower scores on each of the other subscales.

TABLE 13
Normative Data for the MAC Scale

	<i>Mean</i>	<i>SD</i>	<i>Min/Max</i> <i>observed</i>	<i>Min/Max</i> <i>possible</i>	<i>Cancer N = 16 versus</i> <i>Cancer (N =52)</i>	
					MD	Effect size
Anxious Preoccupation	24.0*	3.99	16 -35	9-36	2.19	0.47
Helpless/Hopeless	12.37	4.41	6-24	6-24	4.12	1.27
Fighting Spirit	45.75	8.43	23-64	16-64	7.32*	1.15
Fatalistic	18.67	3.90	10-32	8-32	3.61	0.98
Avoidance	n/a				N/A	

MD=Mean Difference; n/a = data on avoidance were not reported in Greer et al.'s (1989) article. N= 52; mixed diagnosis, various stages (Stage 1 to Metastasis). No information concerning time since diagnosis was provided in the article. *higher scores indicate higher levels of endorsement of the particular coping style

Type C: Lifestyle Defence Mechanism Inventory (LDMI; Spielberger & Reheiser, 2002)

One missing value on the LDMI was replaced with the mean using the SPSS procedure.

Shown in Table 14 are the descriptive statistics for the LDMI. Data for all scales, except the 'harmony relations' subscale were negatively skewed indicating that participants endorsed higher scores. Reliabilities for the two main scales (e.g., Need for Harmony and Rationality/Emotional Defensiveness) were acceptable but the internal consistency of the 'harmonious relations' and 'rationality' subscales was poor.

TABLE 14**Descriptive Statistics: Lifestyle Defence Mechanism Inventory**

	<i>Mean</i>	<i>SD</i>	<i>Min/ Max Obs.</i>	<i>Min/ Max Poss</i>	<i>Skew - Ness</i>	<i>SE Skew- ness</i>	<i>Kur- tosis</i>	<i>SE Kur- tosis</i>	<i>Alpha</i>
N/H	37.52	4.63	30-45	12-48	-.17	.56	-.80	1.09	.73
N/H - Harmony Relations	12.81	1.72	10-16	5-20	.51	.56	-.01	1.09	.32
N/H - Self- sacrifice	14.18	3.03	8-18	5-20	-.70	.56	-.30	1.09	.80
R/ED	36.43	3.57	28-43	12-48	-.30	.56	1.13	1.09	.62
R/ED Rationality	16.50	1.50	13-18	5-20	-1.00	.56	.55	1.09	.22
R/ED Emotional Defensiveness	13.93	2.17	10-17	5-20	-.87	.56	-.84	1.09	.54

Nb: higher scores indicate higher levels of endorsement(i.e. higher need for harmony)

LDMI: Gender differences

As shown in Table 15, there was only 1 significant difference between mean scores on the LDMI subscales when comparing males and females at the $p < .05$ level. Females endorsed higher scores on the ‘rationality’ subscale, however, given the low reliability of this scale this result must be treated with caution.

TABLE 15**LDMI: T-Tests Comparing Means for Females and Males**

		<i>Mean</i>	<i>SD</i>	<i>t</i>	<i>df</i>	<i>P</i>
Need for Harmony (N/H)	F	37.30	4.75			
	M	38.00	4.84	-.268	14	.793
N/H - Harmony Relations	F	12.90	1.64			
	M	12.60	2.07	.323	14	.752
N/H - Self-sacrifice	F	13.90	3.36			
	M	14.80	2.38	-.531	14	.604
Rationality/Emotional Defensiveness (R/ED)	F	37.45	2.65			
	M	34.20	4.60	1.8	14	.092
R/ED Rationality	F	17.00	1.00			
	M	15.40	1.94	2.211	14	.044
R/ED Emotional Defensiveness	F	14.54	1.86			
	M	12.60	2.40	1.773	14	.098

LDMI: Endorsement of items - comparisons with normative data (healthy and cancer)

Shown in Table 16 are the normative data reported by Spielberger and Reheiser (2002) for the Lifestyle Defence Mechanism Inventory (LDMI), incorporating healthy and cancer populations. Shown in Table 16, are the calculations of mean differences between these groups, including the current sample when compared with each of the normative reference populations (i.e. healthy and cancer).

The current sample's scores on the Need for Harmony Scale were higher than the healthy population (Mean difference = 1.92, $d = .33$) but slightly lower than the cancer sample (Mean difference = 1.22, $d = .21$). The current sample scored significantly lower on the 'need for harmony relations' subscale compared with the healthy sample (Mean difference = 3.94, $d = 1.84$) and cancer sample (Mean difference = 4.12, $d = 1.86$).

TABLE 16
Normative Data for the Lifestyle Defence Mechanism Inventory

	<i>Healthy</i> <i>N=585</i>		<i>Cancer</i> <i>N = 151</i>		<i>Cancer</i> <i>(N=151)</i> <i>versus</i> <i>Healthy</i> <i>(N = 585)</i>		<i>Cancer</i> <i>(N= 16)</i> <i>versus</i> <i>Healthy</i> <i>(N = 585)</i>		<i>Cancer</i> <i>(N = 16)</i> <i>versus</i> <i>Cancer</i> <i>(N= 151)</i>	
	Mean	SD	Mean	SD	MD	ES	MD	ES	MD	ES
N/H	35.60	5.74	38.74	6.85	3.14	0.49	1.92	0.33	1.22	0.21
N/H - Harmony Relations	16.75	2.57	16.93	2.7	0.18	0.03	3.94	1.84	4.12	1.86
N/H - Self-sacrifice	13.15	2.81	15.07	3.39	1.92	0.61	1.03	0.35	.89	.27
R/ED	34.13	5.52	35.98	5.2	1.85	0.34	2.3	0.50	.45	.10
R/ED Rationality	16.23	2.31	17.21	2.15	0.98	0.43	0.27	0.14	.71	.37
R/ED Emotional Defensiveness	12.59	3.05	13.71	2.96	1.12	0.37	1.34	0.51	.22	.08

MD = Mean Difference; ES = Effect size; Spielberger and Reheiser's (2002) cancer sample comprised of patients with mixed diagnosis. No information concerning the data of diagnosis was provided in the article

On the self-sacrifice subscale of the Need for Harmony scale, the current sample scored lower than the cancer sample (Mean difference = .89, $d = .27$) but higher than the healthy sample (Mean Difference = 1.03, $d = .35$). They reported higher scores on the Rationality Emotional Defensiveness scale than the healthy sample (Mean difference 2.30, $d = .50$), though scores were approximately the same as the cancer sample (Mean difference = .45, $d = .10$). On the Rationality subscale the current sample endorsed lower scores than the cancer sample (Mean difference = .71, $d = .37$) but higher scores than the healthy sample (Mean difference = .27, $d = .14$). On the emotional defensiveness subscale, patients reported higher scores than the healthy sample (Mean difference = 2.61, $d = .51$) but were comparable, although slightly higher than the cancer sample (mean difference = .22, $d = .08$).

Comparisons within normative data (healthy versus cancer)

Also shown in Table 16 are mean differences and effect sizes comparing the normative data (cancer versus healthy groups). As shown, moderate effect sizes were indicated for comparisons on the Need for Harmony Scale, the self sacrifice subscale of the Need for Harmony Scale, and the rationality subscale of the Rationality Emotional Defensiveness scale. Small effect sizes were indicated for all other subscales.

4.4.3 Emotion Regulation Strategies

Courtauld's Emotional Control Scale (CECS; Watson et al., 1988)

There were 21 missing values for the CES scale; 18 of these missing values were from the same participant who responded to only 1 item out of 7 items for each of the three subscales. This participant's data for the CES scale were not included in mean calculations or subsequent analyses (i.e. the pair wise deletion procedure in SPSS was applied). The 3 other missing values were replaced with the mean using the automated procedure on SPSS.

Means, standard deviations and reliabilities for each of the subscales for the CECS are shown in Table 17. The alpha coefficients indicate that each of the subscales, and the total scale

have adequate internal consistency. Participants' scores on the anger and anxiety subscales were negatively skewed indicating that participants endorsed higher scores. Scores on the depression subscale were slightly positively skewed indicating that patients endorsed lower scores on this subscale.

When considering the distribution of scores for the total scale (i.e. CECS-total) scores were approximately normal with some slight peakedness evidenced by a slightly elevated Kurtosis statistic.

TABLE 17
Descriptive Statistics for the Courtauld Emotional Control Scale

	<i>Mean</i>	<i>SD</i>	<i>Skewness</i>	<i>SE</i>	<i>Kurtosis</i>	<i>SE</i>	<i>Alpha</i>
				<i>Skewness</i>		<i>Kurtosis</i>	
Anger	20.66	4.41	-.74	.58	1.2	1.12	.85
Anxiety	18.4	4.32	-.74	.58	1.2	1.12	.91
Depression	19.73	3.63	.42	.58	.49	1.12	.86
Total	58.8	11.07	.04	.58	2.19	1.12	.85

Nb: higher scores indicate higher levels of endorsement (i.e. higher levels of inhibition)

CES: Gender differences

As shown in Table 18, t-tests indicated that there were no significant gender differences in the mean scores on either the subscales or total scores on the CES.

TABLE 18
CES: T-tests Comparing Mean Scores for Males and Females

		<i>Mean</i>	<i>SD</i>	<i>t</i>	<i>df</i>	<i>p</i>
Anger	F	20.40	5.33			
	M	21.20	1.92	-.32	13	.754
Anxiety	F	18.60	5.14			
	M	18.00	2.34	.24	13	.810
Depression	F	20.70	3.59			
	M	17.80	3.19	1.52	13	.151
CES-Total	F	59.70	13.00			
	M	57.00	6.51	.43	13	.673

CES: Level of endorsement and comparison with healthy sample

Normative data relevant to the CES were reported for males and females by Swan, Carmelli, Dame, Rosehman and Spielberger (1992) according to gender. Thus, comparisons between this sample and normative data were conducted on this basis.

As shown in Table 19, compared with the normative data for the healthy population, mean scores obtained for this sample were higher for the suppression of anger and depression in both the male and female groups. In males, a moderate effect size was indicated for both comparisons whereas for females a smaller effect size was indicated (see Table 19).

Comparisons within normative data (healthy versus cancer)

When comparing the normative populations (cancer versus healthy groups) the largest effect sizes were indicated for the suppression of depression in both males and females, with the effect observed greater in the male group. When comparing the normative populations (cancer versus healthy groups) on other scales (anxiety and anger) negligible differences were observed between these scales as indicated by very low effect sizes.

TABLE 19
Normative Data for the Courtauld Emotional Control Scale

	<i>Males</i>				<i>Females</i>												
	Healthy (N=1,236)	Mean	SD	Cancer (N=157)	Healthy N=(863)	Mean	SD	Cancer N=164	Healthy versus Cancer	MD	ES	Cancer (N=16) versus Healthy (N = 1,236)	MD	ES	Cancer (N=16) versus Healthy (N = 1,236)	MD	ES
Anger*	19.3	4.2	19.0	4.2	18.7	4.5	18.8	4.6	0.26	0.54	0.17	0.26	0.05	1.9	1.7	0.62	0.34
Anxiety*	18.6	4.4	18.8	4.4	17.9	4.4	17.9	4.4	0.2	0.4	0.12	0.04	0.6	0.7	0.17	0.7	0.14
Depression*	20.3	4.3	20.4	4.6	19.2	4.8	19.4	4.9	0.97	1.93	0.56	0.26	2.5	1.5	0.66	1.5	0.35

Nb: higher scores indicate higher levels of endorsement; MD = Mean difference; ES = Effect size.

Weinberger’s Adjustment Inventory (WAI; Weinberger, 1990)

There were 7 items with missing values; 4 of these were for the same item (i.e. “I will cheat on something if I know no one will find out”). These values were replaced with the mean using the procedure available on SPSS. Descriptive statistics for each of the WAI subscales are shown in Table 20. Participants’ scores on the Restraint subscales were negatively skewed indicating that participants endorsed higher scores on these scales. Scores on the distress subscale were positively skewed indicating that patients scored lower scores on these subscales. Scores on the Restraint scale were slightly peaked, however, scores on the Restraint subscale ‘consideration of others’ were markedly peaked indicating that the sample were not homogenous in terms of their distribution of scores on this scale. Internal consistency for the Distress and Restraint scales appear satisfactory, however, as shown in Table 20, the alpha coefficients for the subscales of the Restraint scale (i.e., ‘impulse control’, ‘consideration of others’ and ‘responsibility’) were unacceptably low.

TABLE 20
Descriptive Statistics: Weinberger’s Adjustment Inventory

	<i>Mean</i>	<i>SD</i>	<i>Min/Max</i> <i>observed</i>	<i>Min/Max</i> <i>Possible</i>	<i>Skew-</i> <i>ness</i>	<i>SE</i> <i>Skew-</i> <i>ness</i>	<i>Kur-</i> <i>tosis</i>	<i>SE</i> <i>Kur-</i> <i>tosis</i>	<i>Alpha</i>
Distress	27.76	9.39	17-46	12-60	.511	.56	.21	1.09	.86
Restraint	122.28	9.01	98 – 135	30-150	-1.38	.56	2.46	1.09	.64
Suppression of Aggression	30.81	3.42	24-35	7-35	-1.06	.56	.21	1.09	.59
Impulse control	30.63	4.09	22-37	8-40	-.66	.56	-.21	1.09	.46
Consideration	37.23	2.80	28.8-40	7-35	-1.89	.56	4.8	1.09	.46
Responsibility	23.59	4.16	17-30	8-40	.21	.56	-.88	1.09	.24

Nb: higher scores indicate higher levels of endorsement

Categorising ‘repressors’

As shown in Table 20, participants scored high on the restraint scale and low on the distress scale. The median score for the distress scale in this sample is 26.5 and the restraint median score is 124.44. Using the cross-tabs procedure on SPSS and comparing the frequencies of distress scores (below 27) matching for restraint scores over 70, 8/16 participants (50%) met the criteria to be classified as ‘repressors’ according to Weinberger and Davidson’s (1994; Weinberger, 1990) criteria. Of these, 6 participants were females and 2 were males.

WAI: Gender differences

As shown in Table 21, a comparison of the means for each of the WAI subscales revealed that females had significantly higher scores on the Restraint scale and Restraint subscales including ‘impulse control’ and ‘consideration of others’. Due to the low reliabilities on the latter two measures, these results should be viewed cautiously.

TABLE 21
WAI: T-Tests Comparing Mean Scores for Males and Females

		<i>Mean</i>	<i>SD</i>	<i>t</i>	<i>df</i>	<i>p</i>
Distress	F	27.20	8.91			
	M	29.00	11.37	-.34	14	.73
Restraint	F	125.69	5.85			
	M	114.78	10.82	2.65	14	.01
Suppression of Aggression	F	31.54	3.50			
	M	29.20	2.94	1.29	14	.21
Impulse control	F	32.20	2.69			
	M	27.20	4.81	2.69	14	.01
Consideration	F	38.26	1.75			
	M	34.97	3.55	2.52	14	.02
Responsibility	F	23.67	3.82			
	M	23.40	5.31	.12	14	.90

Emotional Approach Coping Scale (EAC: Stanton et al., 2002)

To enable comparisons with Stanton et al.'s (2002, 2000) data, individuals' mean scores for each item (i.e. 'emotional expression' and 'emotional processing') rather than the mean of total scores were used to calculate the sample means. As shown in Table 22, the scales had excellent reliabilities. Participants generally scored around the mid-range on both scales indicating that participants engaged in emotional expression or processing "a little bit".

EAC: Gender differences

Females (Mean = 2.50, *SD* = .77) appeared to engage in more emotional expression than men (Mean = 1.77, *SD* = .62); however, this difference was not significant at the $p < .05$ level ($t = 2.03$, $df(14)$, $p = .06$). Similarly, females (Mean = 2.90, *SD* = .69) appeared to engage in more processing than men (Mean = 2.08, *SD* = .85), although this difference was not significant ($t = 1.85$, $df(14)$ $p = .07$).

TABLE 22
Descriptive Statistics – Emotional Approach Coping

	<i>Mean</i>	<i>SD</i>	<i>Min/Max</i> <i>Observed</i>	<i>Min/Max</i> <i>Possible</i>	<i>Skew-</i> <i>ness</i>	<i>SE</i> <i>Skew-</i> <i>ness</i>	<i>Kur-</i> <i>tosis</i>	<i>SE</i> <i>Kur-</i> <i>tosis</i>	<i>Alpha</i>
Expression	2.27	.78	1-4	1-4	.38	.56	-.00	1.09	.95
Processing	2.65	.82	1.09-4.0	1-4	-.16	.56	-.54	1.09	.95

Nb: higher scores indicate higher levels of processing and expression

EAC: Level of endorsement – comparison with two samples

Means scores on the EAC scales were compared with two samples: one cancer sample (early diagnosis, breast cancer) and one healthy sample. For emotional expression, Stanton's (2000)

cancer sample (Mean = 3.0, $SD = .72$) reported significantly higher scores (Mean difference = .68, $d = .83$) than the current sample. Stanton's (2000) cancer sample (Mean = 2.95, $SD = .84$) reported similar scores for the emotional processing scale as this sample (Mean difference = .35, $d = .16$)

Shown in Table 23 are comparisons with Stanton's (2002) healthy student population. Stanton (2002) reports data for males and females. Results indicated that males in this study report significantly lower levels of emotional processing as compared with the student population (Mean difference = .37, $d = .47$), with the females reporting slightly more emotional processing than the student population (Mean difference = .11, $d = .15$). For emotional expression, the males reported significantly less emotional expression as compared with the student population (Mean difference = .84, $d = 1.30$). Females also reported less emotional expression as compared with the student sample (Mean difference .35, $d = .62$).

TABLE 23
Normative Data EAC compared with Cancer Sample

		<i>Cancer</i> <i>N= 16</i>		<i>Healthy</i> <i>(Stanton et al. 2002)</i>		<i>Healthy versus</i> <i>Cancer Sample</i> <i>N = 16</i>	
		Mean	SD	Mean	SD	Mean Difference	Effect Size
Emotional Processing	M	2.08	.85	2.45	.71	0.37	0.47
	F	2.90	.69	2.79	.73	0.11	0.15
Emotional Expression	M	1.77	.62	2.61	.62	0.84	1.3
	F	2.50	.77	2.85	.63	0.35	.62

4.4.4 Overlap Among Measures

To assess the extent of potential overlap among coping style measures and emotion regulation measures, a series of correlations was performed. Only those variables with adequate

reliability were included in the analyses. In determining ‘adequate’ reliability a criterion of an alpha coefficient above .60 was applied (Nunnally, 1978). In essence, this decision meant that several of the subscales of measures were not included. Variables excluded due to poor reliability included: ‘fatalism’ (MAC scale): ‘harmonious relations’, ‘rationality’ ‘emotional defensiveness’(LDMI), ‘suppression of aggression’, ‘impulse control’, ‘consideration for others’, and ‘responsibility’(WAI). Tables reporting on the results of these correlations are provided in Appendix F.

A summary of the relationships observed is presented in Figure 3 and described in detail according to each measure.

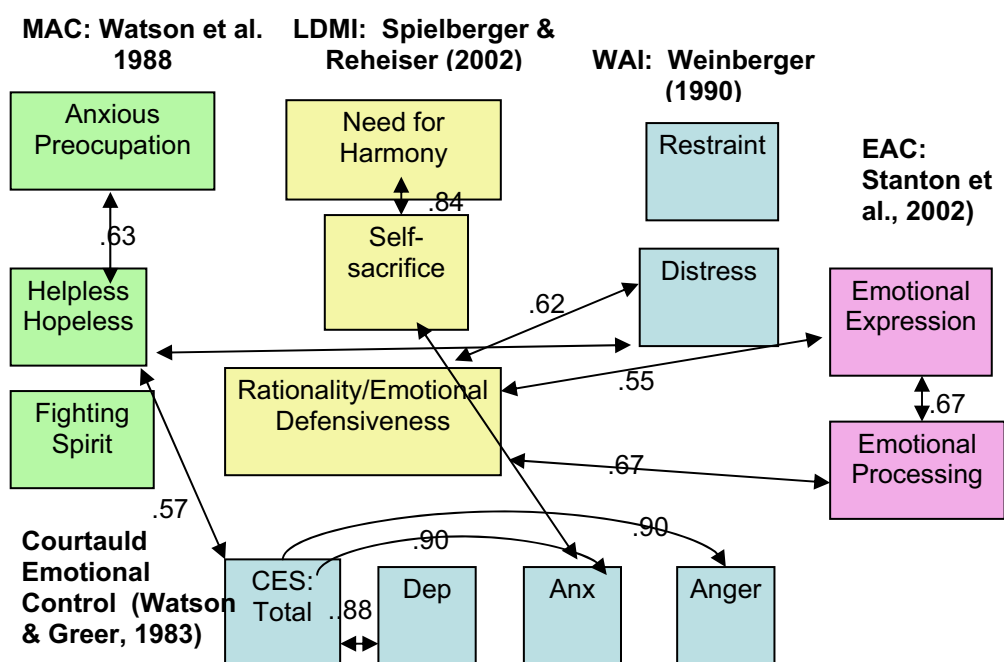


FIGURE 3
Overlap Among Emotion Regulatory Measures and Coping Styles

Mental Adjustment to Cancer

Results indicated that there were no significant correlations between scores on MAC coping styles (e.g., fighting spirit, anxious preoccupation, helpless-hopeless) and the other main

measure of coping style (i.e. Type C/ Lifestyle Defence Mechanism Inventory). However, there was a significant correlation within the MAC coping style scores. For instance, the ‘anxious preoccupation’ and ‘helpless-hopeless’ coping styles were positively correlated ($r = .63, p < .01$). Other results revealed that scores on the MAC ‘helpless-hopeless’ coping style were correlated with measures purporting to assess emotion regulation. For instance, scores on the MAC subscale helpless-hopeless were positively correlated with scores on the depression subscale of the CES ($r = .57, p < .01$) and with scores on the Weinberger Adjustment Inventory Distress scale ($r = .57, p < .05$).

Type C: Lifestyle Defence Mechanism Inventory

The Rationality Emotional Defensiveness scale correlated with the Weinberger Adjustment Inventory ‘distress’ scale ($r = .62, p < .01$), the ‘emotional processing’ ($r = .67, p < .01$) and the ‘emotional expression’ scales ($r = .55, p < .05$). The ‘self sacrifice’ subscale correlated with the CES ‘anxiety’ subscale ($r = .54, p < .05$). As would be expected, the LDMI, Need for Harmony main scale correlated with its ‘self-sacrifice’ subscale ($r = .84, p < .01$).

Weinberger Adjustment Inventory (WAI)

The Restraint scale of the WAI was not correlated with any other measure included in the analyses, although as noted previously, the WAI distress measure was positively correlated with the Rationality Emotional Defensiveness scale ($r = .62, p < .01$).

Courtauld Emotional Control Scale (CES)

The CES scales, and total scores were not correlated with any of the coping style measures, or emotion regulation measures. However, the total score on the CES scale was correlated with each of its subscales (anger: $r = .90, p < .01$; anxiety: $r = .90, p < .01$ and depression: $r = .88, p < .01$).

Emotional Approach Coping Scale

As noted previously the emotional processing ($r = .67, p < .01$) and emotional expression ($r = .55, p < .05$) were correlated with Rationality/Emotion Defence scale. A positive correlation between emotional processing and emotional expression was shown ($r = .67, p < .01$).

4.4.5 Predicting Distress and Quality of Life

To assess the extent to which coping and/or emotion regulation variables might be implicated in indices of adjustment to cancer such as quality of life and/or distress, a series of bivariate correlations was again performed. This time, the subscales of the DASS, the IER and the FACT-G were included in the analyses. Tables presenting these results are shown in Appendix F, along with the other correlations applicable to this Chapter.

Mental Adjustment to Cancer (MAC)

Scores on the anxious preoccupation scale were negatively correlated with FACT-G subscales functional wellbeing ($r = -.61, p < .01$) and emotional wellbeing ($r = -.61, p < .05$).

Similarly, scores on the helpless/hopeless scale were negative positively correlated with FACT-G subscales, functional wellbeing ($r = -.67, p < .01$) and emotional wellbeing ($r = -.58, p < .01$). Scores on the helpless-hopeless subscale were also positively correlated with the IES-R subscale, hyper-arousal ($r = .53, p < .01$). Scores on the fighting spirit subscale were positively correlated with emotional wellbeing ($r = .65, p < .05$).

Lifestyle Defence Mechanisms Inventory (LDMI)

There were no relationships observed between the LDMI, Need for Harmony scales, though Rationality/Emotional Defensiveness was negatively correlated with FACT-G subscales emotional wellbeing ($r = -.56, p < .01$) and physical wellbeing ($r = -.58, p < .01$).

The Weinberger Adjustment Inventory (WAI)

The WAI Restraint scale was not related to any measures of distress or quality of life. The WAI, Distress scale, however, was positively correlated with all of the DASS scales (i.e. stress ($r = .87, p < .05$), anxiety ($r = .87, p < .05$) and depression ($r = .74, p < .05$).

The Courtauld Emotional Control Scale (CES)

The CES anger and anxiety scales were not related to adjustment measures, however the depression subscale was positively correlated with the DASS depression subscale ($r = -.50, p < .01$) and with physical wellbeing ($r = -.51, p < .01$). The total CES scores were positively correlated with DASS depression ($r = .59, p < .01$) and with the FACT-G subscale, spiritual wellbeing ($r = -.59, p < .01$).

Emotional Approach Coping (EAC)

Emotional expression ($r = .49, p < .01$) and emotional processing ($r = .48, p < .01$) were positively correlated with the DASS stress subscale. Emotional expression ($r = .52, p < .01$) and processing ($r = .59, p < .01$) were also correlated with the FACT-G subscale, social and family wellbeing.

Other relationships

Scores on IES-R subscales (i.e. avoidance and intrusion subscales) were unrelated to any coping/regulation variables. Age or time since diagnosis did not correlate with any of the coping and/or emotion regulation variables.

Summary

Shown in Figure 4 is a summary of the results of the analyses that assessed for relationships with outcomes such as quality of life (as measured by the FACT-G and subscales) and distress measures (i.e. DASS and IES-R subscales). It is important to note that none of the

variables showed any relationship with total quality of life scores as measured by the FACT-G. Though some measures (e.g. anxious preoccupation, helpless-hopeless and rationality/emotional defensiveness) did show inverse relationships with sub-domains of the FACT-G. For example, positive spirit showed a positive relationship with the emotional wellbeing subscale of the FACT-G. Both emotional processing and emotional expression were positively correlated with distress (i.e. stress subscale of the DASS) and the spiritual wellbeing scale of the FACT-G.

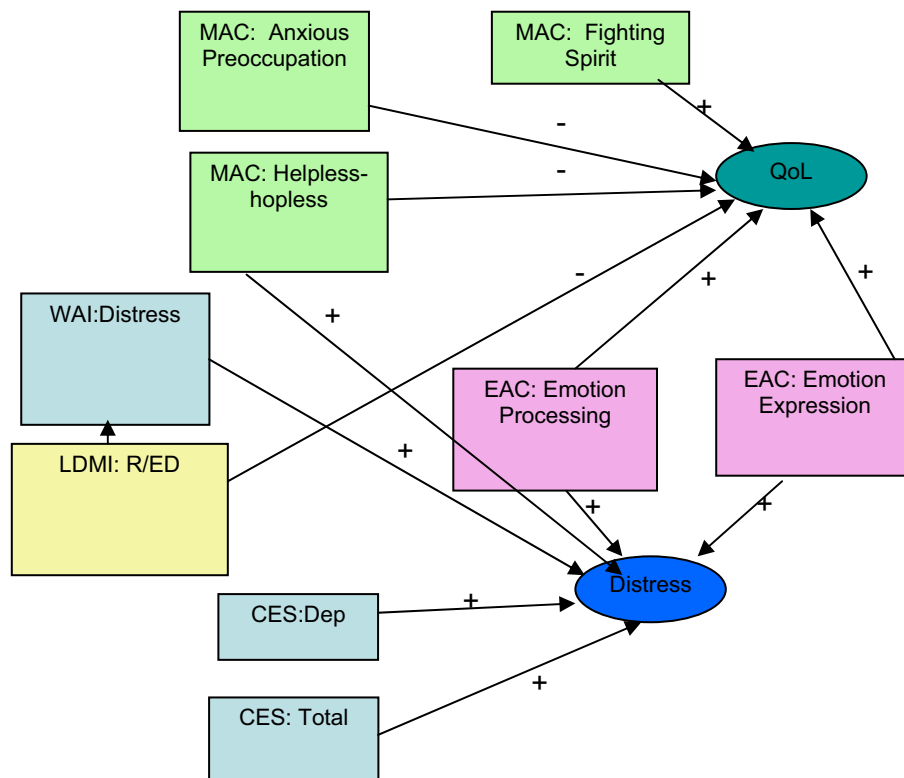


FIGURE 4
Predicting Distress and Quality of Life

4.5 Conclusion

4.5.1 Overview

In this chapter, the main aims were to a) establish the extent to which participants endorsed items indicative of particular coping styles and/or emotional regulation strategies b) assess the extent of overlap between measures of coping style and emotion regulation c) assess for potential relationships between these measures and indices of adjustment such as distress and quality of life. Other aims included to assess for gender differences and to assess the extent of differences in proposed inhibitory styles between normative populations comprised of healthy and cancer populations.

Participants in this study most strongly identified with the ‘fighting spirit’ coping style and 50% of participants met Weinberger’s (1990) criteria to be classified as having a repressive personality style. Generally no gender differences in the endorsement of particular coping styles or emotion regulatory strategies were found, although females scored higher on the rationality subscale of the LDMI. Other results indicated very little overlap among measures of emotional inhibition and the extent to which these measures were associated with measures of adjustment (distress and quality of life) was limited. However, the analyses performed were limited because a number of the subscales of the main measures used in this study had low reliability. From the analysis presented, it was unclear whether these low reliabilities were unique to this study, or were perhaps, indicative of fundamental problems associated with some scales used. In other words, perhaps these measures are not measuring a unidimensional construct of emotional inhibition.

Another possible interpretation for the lack of relationship found among study variables may be that a lack of power, due to the small sample, precluded the detection of these

relationships. Further limitations with respect to the way in which patients were recruited are discussed in the following chapter.

Nevertheless, whilst the literature suggests that emotional inhibition is synonymous with a range of coping styles (e.g., Type C) and/or emotional regulation strategies (repression, suppression, denial), there might be significant conceptual and theoretical differences. In Chapter 5, the aim is to attempt to understand the extent to which 'inhibition' concepts are measured by current tools, and to review the theoretical basis of these concepts. In working towards an understanding of how patients cope with cancer, and the kind of intervention likely to be most efficacious, this approach was considered necessary. For example, in developing an intervention based on the expression of emotion, a complete understanding of the constructs – and measures - associated with inhibition and/or coping style is required. Such an approach may increase the specificity within which the impact of the intervention can be assessed. To avoid repetition, a detailed interpretation of results for this chapter are incorporated into the extended discussion presented in Chapter 5.

5. EMOTIONAL INHIBITION – A CLOSER LOOK AT MEASURES

In this chapter the focus is on interpreting the results presented in chapter 4. A detailed account of the results will be provided to facilitate an understanding of the extent to which measures of coping/emotion regulation are overlapping and/or indeed are measuring the concept of ‘inhibition’. Literature that specifically focuses on the conceptual, theoretical and factor-analytic properties of scales will be presented. When available, normative data and effect sizes reported in Chapter 4 are used to assess the extent to which the coping styles and emotion regulation strategies appear to distinguish cancer patients from the general population.

Furthermore, recent literature that suggests conceptual distinctions among measures of emotional inhibition will be included and discussed with reference to the measures reported in Chapter 4. In addition, the adequacy of existing theory in terms of explaining these concepts, and in explaining the findings observed in this study is considered and alternative explanations proposed. Although not specifically inhibition constructs, a detailed discussion on the MAC coping styles is also presented. These styles are frequently cited in the cancer coping literature and thus the validity of these constructs is also considered. Implications of the findings presented in this chapter are discussed with respect to the utility of the measures particularly in terms of identifying any methodological issues that may impact on the design and/or evaluation of interventions designed to reduce the impact of cancer.

5.1 Mental Adjustment to Cancer (Watson et al, 1989)

5.1.2 Endorsement of MAC Items

According to Greer, Moorey and Watson (1989; Greer et al., 1988) several broad categories of coping predict how individuals adjust to a diagnosis of cancer. These categories (i.e. coping styles) encompass cognitive and behavioural reactions including a) appraisal: “how

the patient perceives the implications of cancer”; and b) their reactions: “what the patient thinks and does to reduce the threat of cancer” (Greer et al., 1989, p. 372). In this study, and when considering the coping style with the highest level of endorsement on the Mental Adjustment to Cancer scale (MAC; Watson et al. 1989) results indicated that participants identified most strongly with the coping style: ‘fighting spirit’. Indeed, the results indicated a very large effect size when the current sample’s scores were compared with the data reported by Greer et al. (1989). Greer et al. (1989, p. 374) suggest that a patient who manifests a fighting spirit coping style is defined as one who ‘[f]ully accepts the diagnosis, uses the word ‘cancer’; is determined to fight the illness tries to obtain as much information as possible about it and adopts an optimistic attitude; may see the illness as a challenge’ (Greer et al., 1989, p. 374).

Greer et al., (1989, p.374) suggest that a patient who endorses items reflective of the anxious/preoccupation coping style:

[r]eacts to the diagnosis with marked persistent anxiety plus accompanying depression, actively seeks information about cancer but tends to interpret this pessimistically; worries that aches and pains indicate spread or recurrence of cancer.

In this study, patients did not endorse this coping style with results indicating significantly lower scores than normative data.

According to Greer et al., (1989, p. 374) an individual with a helpless/hopeless coping style “[i]s engulfed by knowledge of the diagnosis, finds it difficult to think of anything else, daily life is considerably disrupted by fears concerning cancer and possibly, death: adopts a wholly pessimistic attitude”. A very large effect size was indicated when the current sample’s mean

scores were compared with cancer patients in Greer et al.'s (1989) study suggesting that the current sample endorsed significantly lower levels on this coping style.

Other coping styles for which low endorsement in this study was observed included:

Fatalism and Avoidance. According to Greer et al. (1989) a person with a 'fatalistic' coping style essentially accepts their diagnosis but is not active in seeking further information and generally adopts a fatalistic attitude. A person with an avoidant coping style either refuses to accept their diagnosis or minimises the seriousness of the diagnosis. According to Greer et al (1989), the scale does not provide a valid measure of avoidance as the scale includes only one item. Greer et al (1989) suggest that data from participants with elevated scores on this item should be excluded from analyses as their responses may not be valid.

5.1.3 MAC: Overlap with Coping Styles/Emotion Regulation Measures

The relationships observed within the MAC coping scales and between the MAC and other coping/regulation measures were reviewed in Figure 3. Firstly, scores on the hopeless/helpless scale were associated with scores on the anxious preoccupation subscale. Secondly, scores on the hopeless/helpless scale were associated with total emotional control scores (i.e., Courtauld's Emotional Control Scale, CEC; Watson et al., 1983). There were no other associations with other measures of coping style (i.e. Type C personality as measured by the Lifestyle Defence Mechanism Inventory (LDMI: Spielberger & Reheiser, 2002); repressive coping strategies such as Weinberger's Adjustment Inventory (WAI; Weinberger, 1990) or the Emotional Approach Coping Scales (EAC, Stanton et al., 2000).

Evidence for typology of coping styles

The presence of an association between subscales of the MAC (i.e. helpless-hopeless and anxious preoccupation) would suggest that the typology of coping styles proposed by Greer, et al. (1989; Watson et al. 1988) may not be accurate. Instead, the overlap within coping styles shown in this study suggests that the MAC scale is assessing factors that have more in

common than initially proposed. Similarly, the low level of internal consistency indicated for some scales (i.e. fatalism) suggests that items within scales may not be measuring the same constructs. Nordin, Berglunda, Terje and Glimelius (1999) suggest that the original factor analysis reported by Watson et al. (1988) relied on orthogonal rotation which assumes that factors are not correlated. However, Nordin et al. (1999) report that when conducting an exploratory factor analysis with MAC items, 7 items needed to be excluded due to the presence of high correlations among items.

In a further analysis, using an oblique promax-rotated solution, they report that only 28 of the 33 items loaded satisfactorily. The items did not load on the factors as suggested by Greer et al., (1989) and Watson et al. (1988). Nordin et al. (1999) re-labelled the factors to reflect the revised content of each of the factors (e.g., hopeless, positive, anxious and avoidant). The fourth factor 'avoidant' comprised 3 items, in contrast to Greer et al.'s (1989) account where the scale purportedly does not measure avoidance.

Helpless/hopeless and fighting spirit – a continuous measure?

Other studies reporting on the factor structure of a revised MAC version (Mini-MAC; Watson, Law, dos Santos, Greer, Baruch & Bliss, 1994) suggest that fighting spirit and helpless/hopelessness load on the same factor (one positively and one negatively). This finding has led some researchers to combine scores on the helpless/hopeless scale and the fighting spirit scale into one 'fighting spirit' scale (see Classen, Koopman, Angell & Spiegel, 1996; Cordova, Giese-Davis, Golant, Kronnenwetter, Chang, McFarline & Spiegel, 2003). Low scores supposedly indicate a helpless-hopeless style and high scores indicate the presence of a fighting spirit coping style (see Classen et al. 1996). Considerable debate exists between the original authors of the MAC scale regarding the appropriateness of this strategy.

When Watson et al. (1999) failed to replicate a link between fighting spirit and disease outcome, she suggested ‘... that women can be relieved of the burden of guilt that occurs when they find it difficult to maintain a fighting spirit’ (p.1334). In response, Greer argues (2000, p. 355) that “not a shred of evidence is cited in support of this claim, which seems to be based on a misunderstanding of what is meant by fighting spirit”.

Greer (2000) advocates for a bipolar conceptualisation of the fighting spirit/helpless-hopeless construct and suggests that this conceptualisation allows for an explanation concerning the inconsistent results reported between fighting/spirit, helpless/hopeless and disease outcome. Watson, Haviland, Davidson and Bliss (2000) suggest that unlike the full version of the MAC, the Mini-MAC has not been validated and that when the original scale was conceived the helpless-hopeless, fighting spirit responses were conceived as independent dimensions. They further argue that the original MAC measure should be used when attempting to replicate the survival advantage and that the original MAC measure was not intended, or designed to measure a single uni-dimensional construct.

5.1.4 MAC: Predicting Quality of Life and Distress

The anxious preoccupation and helpless-hopeless scales were inversely related to quality of life scores (in particular functional and emotional wellbeing), and similarly, the helpless-hopeless style was associated with stress symptoms (e.g., the IES-R subscale, the hyper-arousal subscale and the WAI distress measure). The presence of a fighting spirit coping style, was not related to reports of distress, although it was associated with the emotional wellbeing subscale of the FACT-G. As will be discussed shortly, any conclusions drawn with respect to the ability of the MAC coping styles to predict outcomes such as quality of life and or distress need to be treated extremely cautiously.

Association between helpless-hopeless and hyper-arousal

The relationship observed in this study between helplessness, hopelessness, and hyper-arousal is interesting, particularly in light of the conclusion drawn in Chapter 3 regarding Seligman's (1975) learned helplessness theory. For instance, it was suggested that exposure to uncontrollable stressors (ongoing threats to life) may leave individuals in a state of hyper-arousal leading to a state of helplessness and depression. Although, given that low scores on the helpless-hopeless subscale were reported in this study, this interpretation may not be applicable.

Overlooked methodological issue – overlap with outcome variables

Nordin et al. (1999) identifies another methodological issue that appears to be overlooked in assessments of the MAC when predicting outcomes such as depression and anxiety. In a second order factor analysis entering MAC factors, along with measures of depression and anxiety, Nordin et al. (1999) showed that items reflecting the original helpless-hopelessness, and anxious preoccupation and fighting spirit subscales loaded on the same factor as outcome variables including depression and anxiety. In other words, not only is there considerable overlap within MAC variables, but there is also considerable overlap between the MAC predictor variables and outcome variables.

According to Nordin et al. (1999), the MAC subscales should not be used as measure of coping style and they cite the work of Lazarus (1993) who suggests that measures of coping should separate concepts such as demand (i.e. stressor), appraisal, coping and outcome. In the case of the MAC scales, the measure was intentionally designed to measure both an individual's appraisal of the demand (cancer diagnosis), and their reaction (i.e. outcome).

5.1.6 Summary: MAC

According to Nordin (1990) et al.'s analysis, it appears that some of the MAC items do measure some aspects of inhibition/denial. Nevertheless, given that the authors of the scale suggest that individuals high in scores on the avoidance subscale should be excluded from analyses then the measure should not be used to measure inhibition. Currently, there appears to be very little evidence for the independence of coping style factors, as conceived in the original research. Similarly, the notion that the hopeless/hopeless items and the fighting spirit items represent a uni-dimensional variable with bipolar opposites lacks empirical validation (Watson et al., 2001). The only evidence cited in support of the construct validity of the fighting spirit scale is the presence of an inverse correlation between these scales (Watson et al., 2001). Systematic studies that empirically assess the validity of this supposed 'fighting spirit' construct, may find that the 'fighting spirit' measure is simply a disease specific measure of optimism and pessimism. Furthermore, the extent to which the 'fighting spirit' concept is different to that proposed in Seligman's (1991) learned optimism theory awaits investigation.

5.2 Lifestyle Defence Mechanism Inventory (LDMI; Spielberger & Reheiser, 2002)

5.2.1 Endorsement of Items

Results indicated that participants in this study endorsed significantly lower levels on the Need for Harmony Relations subscale than a healthy sample and a cancer sample (Spielberger & Reheiser, 2002). Their scores were slightly higher than the healthy sample and lower than the cancer sample on the two main scales: Need for Harmony (N/H) and Rationality, Emotional Defensiveness (R/ED). When compared with the healthy sample, a moderate effect size was indicated for the R/ED and the Emotional Defensiveness subscale with participants in this study reporting higher scores. Generally, the results indicated that on all

other scales, the current sample scored lower than the cancer sample but higher than the healthy sample.

Comparing the healthy and cancer normative populations: Do robust differences exist?

When comparing the mean scores for the normative data (i.e. healthy versus cancer), moderate effect sizes were indicated for the Need for Harmony scale, the self-sacrifice scale and the Rationality scale. On all other measures small effect sizes were indicated. On the Need for Harmony Relations subscale no difference in mean scores between the cancer and healthy population was evident.

5.2.2 LDMI: Unacceptable Reliabilities

With the exception of the 'self-sacrifice' scale (a subscale of the NH scale), all other subscales had unacceptable levels of reliability. According to Nunnally (1978) alpha coefficients should not be lower than .60 for research purposes. In reviewing literature that reports on the construction of the LDMI scale (Spielberger & Reheiser, 2002), it appears that the low reliabilities reported in Chapter 4 were not simply a function of the small sample, or accuracy of data entry. Instead, the lower reliabilities for subscales appear to be related to decisions made during the construction of the scale. For example, when the LDMI scale was constructed, the eigenvalues reported for some item loadings were in some cases lower than .50; yet they were retained in subscales as they were judged to group together meaningfully. Whilst this approach is generally accepted in the literature, the extent to which the subscales provide any additional information, as compared with retaining all factors in the one dominant factor, is unknown.

Low reliabilities due to scale construction?

When describing the item content of the need for harmony relations subscale, Spielberger and Reheiser (2002, p. 19) describe it "... as a general lifestyle that emphasizes the need to have harmonious relations with other persons". The second factor, labelled as self-sacrifice is

described “... as a willingness to sacrifice one’s own needs in order to maintain such relationships”. In reality, the items are worded so that each factor is dependent on the other. For example, “I am willing to make self-sacrifices to maintain smooth relationships with people I care about”. The authors of the scale report that considerably more of the NH scale items loaded onto the factor, labelled ‘self-sacrifice’ in their cancer patient sample suggesting that this may be the more pervasive factor in terms of meaning as opposed to a need for harmony. Furthermore, they report that higher mean scores on 8/12 ‘need for harmony’ items were observed in the cancer sample as compared with the healthy group; this difference was particularly robust on the items loading highly onto the ‘self sacrifice’ factor.

In this study, the largest effect size ($d = .61$) was indicated for the ‘self-sacrifice’ scale when comparing the two normative groups, thus suggesting that the self-sacrifice factor may indeed be the more dominant factor that discriminates between cancer and healthy populations. Though, in the current sample, a small effect size was observed for the higher scores on the self-sacrifice scale when compared to the healthy group.

As noted, low reliabilities in this study were also found for the R/ED subscales, ‘rationality’ and ‘emotional defensiveness’. Again, a consideration of the factor analysis results reported by Spielberger and Reheiser (2002) suggests that this finding is not surprising. In their cancer sample, as compared with and a non-patient group, 10/12 scale items loaded more highly onto one main factor (i.e., originally named Rationality). The remaining two items loaded onto a smaller second factor and included questions that dealt with the use of rational thinking to inhibit aggression when treated unfairly. For example: “If someone deeply hurts my feelings, I may attack them or respond purely emotionally [reverse coded] and “I try to understand other people even if I do not like them”.

According to Spielberger and Reheiser (2002), their cancer samples' scores were significantly higher on these items. This finding was interpreted by them as indicating that cancer patients have considerable difficulty expressing anger. Despite these findings, that indicated a factor structure that could discriminate the cancer population from the other groups, the total scale was divided into a further 2 subscales: rationality and emotional defensiveness. The two items that appeared to discriminate the cancer sample from the other samples (inhibition of aggression) along with 3 others (i.e., that originally loaded dominantly on the Rationality factor) were used to form the new subscale, 'emotional defensiveness'. The decision to divide the scale into two separate scales appears to be a poor one and creates difficulties in terms of reliability (i.e. internal consistency), and poses difficulties for the interpretation of the results.

5.2.3 LDMI: Implications of factor structure

In light of the complexities reviewed in terms of understanding the factor structure of the LDMI, how might the results of this study be interpreted? Firstly, it appears that in discriminating between the cancer patient groups, and the non-patient groups, the important factors in Spielberger's earlier research may be best described as involving self sacrifice and rationality. Rationality, using the full scale appears to comprise the tendency to use rational and logical thinking though it also appears to describe a tendency to inhibit emotional reactions. Thus in this study, it appears that the current sample would be described as having a coping style described as dominantly self-sacrificing and high in rational and logical thinking, possibly incorporating the tendency to inhibit emotional responses. However, the extent to which these items are independent measures of emotional defensiveness, as opposed to rationality, is dubious. As indicated in the following example, all items that comprise the emotional defensiveness scale contain aspects of logic, reasoning and understanding:

1. When I am in a situation in which I strongly disagree with other people, I try not to show my emotions.

2. If anyone deeply hurts my feelings, I still try to treat them reasonable and to understand their behaviour.
3. I try to understand other people even if I do not like them.
4. If someone acts against my needs and desires, I still try to understand him/her.
5. My use of reason and logic prevents me from attacking others, even if there is good reason to do so.

5.2.4 LDMI: Overlap with Other Measures

Evidence for type C conceptualisation?

The R/ED and NH scales were not associated with other coping style measures (i.e. the MAC) or emotion regulation strategies such as repression (i.e. as purportedly measured by the Restraint subscale of the WAI) or with total emotional control scores (i.e. suppression as measured by the Courtauld Emotional Control Scale; CES; Watson & Greer, 1983). The self-sacrifice subscale (the only subscale with acceptable reliability) was positively associated with the tendency to control feelings of anxiety (i.e. suppression of anxiety as measured by the CES scale). This finding may suggest that those participants scoring higher on self-sacrifice tend to put the needs of others before their own emotional needs. This finding would be consistent with a Type C personality account. Spielberger and Reheiser (2002, p. 4) define individuals with a Type C personality as “nice, cooperative, and sensitive to the needs, feelings and concerns of other people noting that such individuals may not even admit to, or recognize, ever being angry”.

LDMI as a measure of repression?

Findings with respect to the R/ED scale and associations and/or overlap with the Emotional Approach coping scale and Weinberger’s (1990) distress measure are considerably more difficult to interpret. According to Spielberger (1988; Spielberger & Reheiser, 2002), scores on the R/ED scale measure the extent to which an individual uses rational/non-emotional reactions in interpersonal situations with high scores on the LDMI indicating that an

individual shows a tendency to use defensive mechanisms such as repression and/or denial. According to Spielberger and Reheiser (2002) the theoretical background that guided the development of the scales was based on the work of Lazarus (1966, 1991) and Freud (1894, 1946). For instance, they conceive of concepts such as repression and denial as emotion focused coping mechanisms in the sense that they are maladaptive (as per Lazarus & Folkman's, 1984 account) and define 'repression' in terms of the Freudian psychological defence mechanism. For instance, citing the work of Laughlin (1963), they propose that:

Psychological defence mechanisms function to protect a person from experiencing the unpleasant feelings associated with intense emotions by modifying, distorting, or rendering unconscious, the thoughts and memories of traumatic experiences.

Spielberger and Reheiser, 2002, p.2

Results contrary to theoretical propositions

Contrary to these theoretical premises, scores on both EAC measures (i.e. the emotional processing scale and the emotional expression scale) and Weinberger's (1990) distress scale were positively correlated with scores on the R/ED scale. Therefore, the results suggest that the more one engages in rationality/emotional defensiveness the more one engages in emotional processing and emotional expression. Based on the theoretical premises proposed, it was expected that R/ED would correlate negatively with the EAC scales; that is, supporting the premise that the R/ED was associated with non-emotional thought and processing.

Similarly, the authors of the LDMI propose that when repression is active and strong (i.e. purportedly as indicated by high scores on the R/ED scales) an individual will not recall the event that triggered an emotional reaction and the individual will not experience the emotion. In contrast, "if repression is weak, however, or if there is a partial breakdown in repression,

derivatives of the original experience can once again precipitate an emotion reaction” (Spielberger and Reheiser, 2002, p. 2). In other words, if repression is strong then we would expect that patients would under report distress thus we should observe an inverse relationship between R/ED and measures of stress, not a positive one.

Relationship with emotional approach coping scales – active processing?

According to Stanton et al. (2002), the EAC scale was developed based on the notion that emotional processing and expression is adaptive. The authors postulate that emotional approach coping involves 3 distinctive strategies a) emotional identification (e.g., maintaining self-awareness and active acknowledgement of one’s emotional states b) emotional processing (e.g., actively exploring meanings in order to understand one’s emotions c) emotional expression (incorporating interpersonal and intrapersonal forms).

Although participants, on average, endorsed that they engaged in emotional approach coping (“a little bit”) the correlation between scores on the R/ED and EAC scales may suggest that rationality/emotional defensiveness is associated with considerable ‘conscious’ identification, engagement and understanding of emotions.

Individuals may overcompensate by processing positive emotion

Central to theories of repression is that negative emotion is repressed. The association between EAC coping styles and the R/ED does not necessarily suggest that negative emotions were being processed and/or expressed. For instance, Stanton et al.’s (2002) measure does not discriminate between negative and positive emotions. For instance, a possible interpretation of this relationship between the EAC and R/ED scales could indicate that individuals with a tendency to inhibit negative emotion overcompensate by engaging in emotional processing and expression involving positive affect.

Empirical studies support the view that individuals described as repressors like to promote themselves in a favourable light and will go to extraordinary lengths to do so. For instance, previous research indicates that individuals high in repressive tendencies ('repressors') like to present themselves in socially desired ways and spend more time processing information when given unfavourable feedback in public versus private, and when compared to non-repressors (Baumesister & Cairns, 1992).

5.2.5 LDMI: Predicting Quality of Life and Distress

In this study scores on the R/ED were inversely related to the emotional well-being scales and the physical wellbeing scales suggesting that the more one applies a rational and emotionally defensive coping style, the more impaired is one's quality of life. The LDMI scales were not related to distress (either as measured by the DASS or the IES-R), although as noted they were positively correlated with the WAI distress measure.

5.2.6 LDMI: Review of Main Conclusions

LDMI and type C personality

First with respect to the assessment of the Type C personality pattern, the LDM scales appear to provide a reasonably valid assessment of this coping style, as described by Spielberger and Reheiser (2002) and others (e.g. Morris, 1980). However, the NH scale is probably more consistent with the Type C construct, as definitions of the Type C pattern do not necessarily emphasise rational thought, and as reviewed, the R/ED scale appears to be heavily loaded with items emphasising 'rationality'.

Does the LDMI discriminate between cancer and healthy populations?

Currently, when using the item groupings as recommended by Spielberger and Reheiser, (2002), the extent to which the LDMI measure can discriminate individuals who develop cancer versus those who do not, appears uncertain. Previous research for example, suggests

that individuals with the Type C personality pattern are more susceptible to developing chronic illnesses such as heart disease and cancer (Grossarth-Maticek, 1979, Temoshok & Fox, 1984). However, given that scores from cancer samples were not significantly different on the need for harmony relations scale then one would query the extent to which this type of coping style is observed in members of the general population who do not go onto develop chronic illnesses such as cancer. As reviewed, particular item groupings observed during construction of the scale (i.e. self-sacrifice and rationality) did appear to discriminate between the cancer and non-cancer populations but the eventual scales determined to be most meaningful (despite nebulous factor loadings) appear to do this less well.

Unconscious versus conscious processes?

The central difficulty in explaining the findings of this study is that those participants with higher scores on the R/ED also reported higher levels of distress suggesting that participants are conscious of their distress. Theoretically, Spielberger and Reheiser (2002) suggest that when individuals engage in rational and non-emotional thought, any negative affect is repressed and not conscious. The findings in this study clearly contradict this claim.

Weinberger and Davidson (1994, p. 6) suggest that not all processing of negative affect is unconscious and that repressors employ a range of strategies from obliquely conscious (“I’m becoming anxious but will vigorously act as if it is not true to protect my private self image”); to rigid suppression (“I do not want to believe that I am anxious, so I will not think about information to the contrary”); to complete unconscious awareness (e.g., “I am not anxious and cannot understand why anyone would claim that I am”).

In considering an alternative explanation for these findings, perhaps the act of repression is not ‘unconscious’ at all, but instead involves effortful processing. Erdelyi (2001) suggest that empirical findings do not support the view of a distinction between unconscious and conscious processes. As noted in Chapter 4, Pennebaker (1997) suggests that active

inhibition of emotion is a form of psychological work. This inhibitory work, which is reflected in autonomic and central nervous system activity, could be viewed as a chronic low level stressor (Pennebaker, 1997). This view could account for the current findings, as those individuals high in rationality and devoid of emotional reactions, report higher psychological distress. A range of experimental studies, for example, suggest that individuals with a repressive coping style have heightened physiological responses, however, they do not generally acknowledge (in self report measures of distress) that they are distressed (Asendorpf & Scherer, 1983; King, Taylor, Albright & Haskell, 1990; Kneir & Tomosok, 1984; Weinberger, Schwartz & Davidson, 1979).

Incorporating contemporary theory

Moving somewhat away from Freudian concepts of defence mechanisms and repression, and adopting an information processing account, the act, for instance, of engaging in rational thought (and possibly repressing negative thoughts/emotions) at a cognitive level would require the allocation of cognitive resources. Incorporating cognitive theory, Quartana, Laubmeier & Zakowski (2006, p. 487) suggest that:

... stressful experiences challenge pre-existing mental sets, or schemas, that contain information about an individual's past experiences as well as core beliefs, assumptions and expectations concerning future events. Intrusive thoughts and images surrounding stressful events will inevitably begin to suffuse conscious awareness, breaking through avoidance-based coping mechanisms.

According to Quartana et al. (2006, p. 487) distress will continue to be experienced until an individual confronts aspects associated with the stress or trauma experienced. Confrontation enables the facilitation of effective processing by enabling an individual to "reinterpret, contemplate and accept confusing and threatening aspects of the stressful experience, consequently fostering harmonisation of present information and pre-existing schemas".

It could be argued that in this study, participants had entered into a stage of confrontation (i.e. having agreed to be interviewed and having already shared their experiences with coping with cancer (see Chapter 6). Such a confrontation, may have led to some transient increases in distress for some participants. A test of this hypothesis will be presented in Chapter 8 when distress scores pre and post the research interview are presented.

LDMI as a measure of inhibition?

From the analysis and discussion presented, to what extent can one can infer that the LDMI is measuring inhibition? Given that the LDMI is conceived as an indirect measure of repression then a definitive conclusion is difficult. The fundamental question concerns the extent to which a measure highly loaded with items emphasising rationality, is synonymous with repression. When conceiving of repression as defined in Freudian terms (i.e. as a defence mechanism) the results in this study do not suggest that the R/ED is measuring repression. For example, higher R/ED scores were associated with conscious reports of distress and emotional processing and expression. However, as reviewed, cognitive processing accounts may better serve to explain the act of repression in terms of conscious and deliberate processing. In light of the lack of a correlation between the WAI restraint scale and R/ED scores there is little evidence that the R/ED measure assesses repression. Admittedly, though some items within the R/ED do appear to tap a construct that involves the inhibition of emotion, the fact that most of the items in the R/ED scale emphasise rationality, it can be concluded that use of the R/ED exclusively as a measure of emotional inhibition is limited.

5.3 Courtauld's Emotional Control Scale

5.3.1 Endorsement of Items Measuring Emotional Control

The emotional control scale purportedly measures the extent to which cancer patients control the expression of emotional states such as depression, anxiety and anger. Giese-Davis and Spiegel (2001) suggest that this form of emotional inhibition is synonymous with the concept

of suppression but that it differs from repression in that it does not appear to be as pervasive a coping strategy.

Watson and Greer (1983) have reported that scores on the emotional control scale are negatively correlated with measures of Type A behaviour (i.e. the inability to control emotional outbursts), and with measures of anxiety as measured by Spielberger's (1979) State-Trait Personality Inventory. The scale was initially developed from interviews with patients on admission prior to receiving a diagnosis. Interview questions focused on how patients generally responded to feeling angry, depressed, or anxious. As compared with normative data provided by Swan et al. (1992), male and female participants in this study reported significantly higher mean scores on the control of anger than a healthy and cancer patient sample. Females reported higher scores on the tendency to inhibit depression as compared with the healthy and cancer patient sample. When assessing the differences between the healthy and cancer groups as reported by Swan et al. (1992), male and female cancer patients showed increased tendencies to inhibit depression but there were no differences on other scales (anger and anxiety).

5.3.2 CES: Overlap with Other Measures

In this study, all subscales and the CES total score had adequate levels of reliability thus all subscales were included in correlational analyses. The extent of overlap, as indicated by high correlations with total CES scores and the depression, anger, and anxiety subscales does suggest that the measure is tapping into a more general – and perhaps uni-dimensional construct - of emotion control. As noted earlier in this discussion, a positive correlation exists with overall CES scores (control over emotions) and scores on the helpless-hopeless scale. Furthermore, the relationship between the R/ED and the CES anxiety scales does suggest that some form of emotional inhibition/ emotional control is being tapped. The CES total scores showed no relationship, however, with the R/ED total scores, or with the Restraint measure of

the WAI measure perhaps suggesting that this construct is different from other measures purportedly measuring repression.

5.3.3 CES: Predicting Quality of Life and Distress

The CES depression scores were negatively correlated with the physical well-being and spiritual wellbeing of the FACT-G but along with total CES scores were positively correlated with DASS depression scores. In other words, a similar pattern was observed as with the R/ED scale in that those participants supposedly in control of their emotions had lower quality of life scores but increased psychological distress, in this case, as measured by the depression scale of the DASS.

Inhibition and reports of distress

This finding contradicts the proposal that those individuals who inhibit emotion also report reduced levels of psychological distress. Whilst this finding appears to be contrary to expectations, other researchers cite higher levels of mood disturbance with higher levels of emotional control in support for the hypothesis that emotional control results in maladaptive adjustment (Classen, et al. 1996; Cordova et al, 2003). In understanding the relationship with spiritual wellbeing, it may be that those who inhibit emotions such as depression and who also report higher scores on the hopeless-helpless dimension of the MAC genuinely perceive less meaning and/or peace in their lives. Alternatively, perhaps as argued previously with reference to the MAC scales, they may be higher in negative affect and or pessimism, and thus may respond negatively to a range of distress/quality of life measures.

5.3.4 CES: Summary

The CES measure does appear to assess the extent to which an individual generally inhibits or controls emotions. In this sample, the tendency to inhibit anger (but not anxiety or depression) was indicated for males. For females, the results showed that they inhibited the expression of emotional states such as depression and anger but not anxiety. Individuals from

non-patient samples also show a tendency to inhibit emotional states such as depression. Nevertheless, the pattern of results observed does appear to suggest that cancer patients in the current sample do appear to control the expression of anger more than the general population. The finding with respect to the inhibition of emotional states such as depression in non-patient samples may be a consequence of the general stigma that exists at a population level concerning admitting that one has mental health issues, such as depression.

In summary, the extent to which the inhibition of emotion is a coping strategy only applicable to individuals with cancer and/or other chronic illness groups has not yet been determined. Nevertheless, this measure does appear to be valid in terms of the construct it purports to measure (i.e. the control/inhibition of emotions). Furthermore, the measure may prove to be useful particularly in terms of assessing changes in emotion regulation strategy (i.e. from inhibition to expression) pre and post an intervention. However, the extent to which the measure can be considered to measure a construct with expression and inhibition as bipolar opposites remains untested.

5.4 Emotional Approach Coping

In this study, participants indicated that they engaged in emotional processing and expression “a little”. Compared with Stanton’s (2002) cancer sample, males and females reported similar levels of emotional processing but reported lower scores for emotional expression. When compared to a healthy population (Stanton et al. 2000), males reported less emotional processing, and both males and females reported significantly lower levels of emotional expression.

5.4.1 EAC: Overlap with Other Measures and Relationship with Distress

As reviewed previously, the EAC scales were shown to have a positive relationship with the R/ED scale of the LDM suggesting that those high in R/ED showed a tendency to express and process emotions. As noted, Stanton et al. (2002) propose that the processing and expression

of emotion is adaptive, not maladaptive as has been proposed in previous coping studies (e.g. Lazarus & Folkman, 1984). However, Stanton et al. (2002), report that men with higher scores on the emotional processing measure were more likely to ruminate and use distraction when depressed.

In this study, higher scores on the EAC scales were associated with greater distress, specifically on the DASS stress scale, but not the WAI distress scale. This finding suggests that the results are not a result of a general perception of low-wellbeing or self-esteem (i.e. as measured by the WAI distress scale), but represent stress as it is conceived in the DASS as indicating symptoms of stress. This finding does not necessarily mean that the expression of emotion results in increased distress, and instead, this finding could be interpreted as those individuals high in distress are engaging in emotional approach coping which ultimately may prove to be adaptive.

5.4.2 Summary: Emotional Approach Coping

The constructs of emotional processing and emotional expression do appear to be psychometrically sound with high internal consistency evident within each subscale and also between the two scales, perhaps suggesting that the scale does assess a form of emotional approach coping. Whether the measure is assessing a coping strategy versus a dispositional construct has not yet been empirically determined. For instance, to date assessments of the extent of similarity or difference with concepts such as Emotional Intelligence (Goleman, 1995) await investigation. Furthermore, the measure does not distinguish between the processing and expression of negative or positive emotions and this would appear to be important particularly when used in combination with measures of emotional inhibition.

For instance, Quartana et al. (2006) show differential outcomes on measures of avoidance and intrusions (i.e. as measured by IES-R) depending on the type (i.e. positive or negative) and

amount of emotional expression. Such an approach would also appear particularly necessary in establishing whether emotional approach coping is adaptive or maladaptive.

Nevertheless, the measure does offer some utility in assessing the extent to which one might report that they engage in emotional processing or expression. This would appear to be particularly useful when assessing the effectiveness of interventions focused on the expression of emotion. For instance, Stanton et al. (2002) suggest that whilst the measure is designed to assess a dispositional tendency towards emotional approach coping, this tendency might be altered by experiences. In other words, it may be amenable to intervention, although to date this claim has not been assessed empirically.

Furthermore, given that emotional approach coping is positively correlated with quality of life measures, this finding could suggest that those individuals who acknowledge their distress and who use emotional approach coping strategies, have improved quality of life. Moreover, the positive relationship observed between the emotional approach coping scales and social and family wellbeing may be particularly important in understanding the needs of cancer patients.

5.5 Weinberger's Adjustment Inventory (WAI; Weinberger, 1990)

5.5.1 Endorsement of Distress and Restraint Items

According to Weinberger and Davidson (1994; Weinberger & Schwartz, 1991) individuals who score very high on the restraint subscale of the WAI and very low on the distress subscale of the WAI can be classified as repressors. In other words, consistent with Freudian notions of repression, individuals who supposedly adopt a coping style that relies on the use of defence mechanisms will be in denial of their distress. Weinberger and Davidson's (1994) account differs from that proposed by Spielberger and Reheiser (2002) in that they suggest that not all repression occurs at an unconscious level.

As per the results reported in Chapter 4, 50% met the criteria as described by Weinberger and Davidson (1994) to be classified as a repressor. Thus based on Weinberger and Davidson's (1994) proposals and the extensive experimental literature that shows that repressors underestimate their levels of distress¹⁴, this finding suggests that over half of the participants in this study may be significantly underreporting their levels of stress, and possibly overestimating their quality of life.

5.5.2 Overlap with other Measures

The WAI comprises two main scales, Distress and Self-Restraint. The Distress scale

... provides a general measure of individuals' tendencies to feel dissatisfied with themselves and their ability to achieve desired outcomes...Proneness to anxiety, depression, low self-esteem, and low wellbeing are operationally defined as subtypes of distress

Weinberger & Schwartz, 1991, p. 382

The subscale scores were not calculated in this study, as other more specific measures of stress, depression and anxiety were included (i.e. the DASS). Indeed, the sole purpose for inclusion of the Distress scale was that, according to Weinberger and Davidson's (1994) conceptualisation of repression, scores were important in terms of categorising repressors. Thus, the WAI distress scale was not used as an outcome in the analyses presented in Figure 4 in Chapter 4. Nevertheless, the inclusion of the WAI distress measure in assessments of the overlap among variables used in this study (as described in chapter 4) revealed some interesting findings that helped when interpreting results pertaining to the MAC coping styles.

¹⁴ Note that considerable work has also been reported whereby repressors are identified using measures of anxiety such as the Taylor (1953) Manifest Anxiety Scale and the Marlow-Crowne Social Desirability Scale (Crowne & Marlowe, 1964). In such research repressors are distinguished from 3 other groups: low anxious, high anxious, defensive high anxious (see Weinberger, Schwartz & Davidson, 1979).

As noted, the helpless-hopeless scale was positively associated with distress as measured by the WAI but not the DASS and it was suggested that the helpless-hopeless scale may be measuring a general tendency such as negative affectivity or pessimism. When considering the conceptual definition of distress as offered by Weinberger and Schwartz (1994) it appears that the emphasis on “the ability to achieve desired outcomes” probably represents significant overlap with the helpless-hope-hopeless items in the MAC scale (e.g., I feel that nothing I will do will make a difference”). In other words, rather than the helpless-hopeless variable showing any true predictive relationship with adjustment outcomes such as distress, the relationship – as was cautioned by Nordin et al. (1999) – may represent a statistical artifact due to the similarity in items.

The results presented here focus on the Restraint scale, as results relevant to the Distress scale have been reported in previous sections. Restraint is defined as:

encompass[ing] domains related to socialization and self-control and refers to suppression of egoistic desires in the interest of long-term goals and relations with others. Thus, restraint is superordinate to tendencies to inhibit aggressive behaviour, to exercise impulse control, to act responsible (sic), and to be considerate of others.

Weinberger & Schwartz, 1991, p. 382

The results indicated that subscales specified for the Restraint scale had unacceptable reliabilities. Based on the results of inter-item correlations, and confirmatory factor analysis reported by Weinberger (1997), the results of the analyses performed on this study’s data were expected to yield considerably higher alpha coefficients. Thus, all data were double checked for accuracy and scales were checked for the correct inclusion of items. However, no errors were identified. Determining ‘why’ these scales have such low reliabilities is difficult

because the level of detail provided by Weinberger (1997) is not as extensive as provided by authors of other scales (e.g., Spielberger & Reheiser, 2002).

Weinberger (1997) reports high alpha coefficients for all subscales; although slightly lower alphas were indicated for the subscales than for the main Restraint scale, though none was lower than .68. Furthermore, Weinberger (1997) when conducting confirmatory factor analysis reports virtually perfect results using ESQ for Windows (a program not widely used in the discipline of psychology and thus not familiar to this researcher) indicating that the factors account for all but 3% of variance.

This is an unusually high amount of variance and it appears that this may have occurred due to extensive multi-collinearity among the items. Indeed, Weinberger (1997) suggests that subscales were correlated, however, the level of associations was not reported. As discussed shortly, the most recent approach to categorising the 'repressor' emphasises the main factor Restraint, which in this study had acceptable reliability.

Restraint: a measure of inhibition, repression or coping style?

In this study, the Restraint scale was not correlated with any other measure of emotion regulation or coping style. Given that the CES does appear to genuinely measure emotional inhibition, then this finding suggests a) that the restraint scale measures some other kind of emotional regulatory strategy, perhaps repression b) that repression and emotional control are not directly related. However, what evidence is there that the Restraint construct is measuring a genuine repressive coping or personality style? Debate exists, for example, regarding the extent to which repression can be considered a coping strategy as opposed to simply a style of socially desirable responding (Furnham, 1986). Furnham, Petrides, Sistierson and Baluch (2003).

WAI as a measure of preservation of a favourable self-concept?

In a review of 59 studies, repressors consistently report more positive self-images, better adjustment and high levels of optimism than non-repressors. Furnham et al., (2003) demonstrate the pervasiveness of this effect by showing that repressors rate themselves as highly intelligent, and emotionally brighter than non-repressors:

Repressors generally 'presented' themselves as intellectually and emotionally brighter than the other groups. While there is little evidence that repression is linked to cognitive ability, it does seem that the repressive coping style is almost antithetical to the conception of the emotionally intelligent person. Thus, while repression is about the denial and suppression of (negative emotions) EI involves coming to terms with, and where appropriate displaying, such emotions. In spite of this, the repressor group had the highest total trait EI scores.

Furham et al., 2003, p. 235

Weinberger (1990) argues that repression is more than the preservation of 'self concepts' and suggests that repressors have a deficit in emotion regulatory strategy. For example, in an experiment comparing repressors with impression managers all participants were led to believe that they would be criticised if they failed to follow the experimenter's instructions to self-disclose. There were 2 conditions: inhibition and expression. Repressors in both conditions responded with inhibition. An alternative explanation for these findings is that perhaps those scoring high in restraint really are more socially adept than others.

Proposed distinctions among inhibitory constructs

Garssen (2007) suggests that conceptualisations of repression can be distinguished by the extent to which repression is socially or personally related. He suggests that constructs that assess for personally related repression include emotional control, as is measured by the CES and Rationality as defined by Spielberger and Reheiser (2002). These conceptualisations refer to a general tendency to inhibit emotional states such as anxiety, depression and anger,

and also include attempts to avoid being influenced by negative feelings. In contrast, measures such as Weinberger's (1991) Restraint scale refer to repression that is socially related. For example, self-restraint refers to a coping style that shows a tendency towards inhibiting aggressive behaviour, maintaining impulse control, acting responsibly and being considerate of others in order to achieve relations with others.

Suppression and repression: distinct constructs?

In support of this view, Garrsen (2007) cites the work of Giese-Davis and Spiegel (2001) who conducted a second order factor analysis showing that the CES scales loaded onto a separate factor from that of the WAI Restraint scales. In this paper, Giese-Davis and Spiegel (2001) suggest that CES is analogous to suppression and the WAI Restraint scales are analogous to Repression.

5.5.3 WAI: Predicting Distress and Quality of Life

Findings contrary to theory?

In this study, Restraint was unrelated to any measure of distress or quality of life. This finding is somewhat paradoxical. It would appear logical that, at the very least, scores on the WAI distress scale would be inversely related to scores on the Restraint Scale. Moreover, one would expect that higher levels of restraint, which supposedly indicates higher levels of repression, would show an inverse relationship with other distress measures in this study. In a recent article, Pauls (2007) criticises an early meta-analysis performed by DeNeve and Cooper (1998) on similar conceptual grounds.

When comparing a range of personality measures, repression showed the most pervasive effect on subjective well being as indicated by a negative correlation. In other words, such a finding is antithetical to the repressive style that assumes that individuals high in repressive style underestimate distress on self-report measures (DeNeve & Cooper, 1998). A similar pattern was observed in this study, not for Restraint, but for the other measures of inhibition

whereby an inverse relationship was shown between R/ED and CES and some domains on the FACT-G and a positive relationship between R/ED and distress.

Dimensions versus Categories?

Weinberger and Schwartz (1991) argue that the dimensional approach used in most psychological research, and associated statistical analyses (i.e. correlations, multivariate analyses), is inappropriate for assessments of variables that are better defined in categories rather than dimensions. For instance, Weinberger and Schwartz (1991) extend the concept of the repressive coping style beyond psychoanalytic theory and instead incorporate it into contemporary personality theory. Weinberger and Schwartz's (1991) most recent conceptualisation of repression conceives of Restraint and Distress as superordinate factors within a hierarchical structure. The account is similar to that advocated for by other personality theorists such as Costa and McCrae (1992) when describing the Big 5 Personality Factors. Weinberger and Schwartz (1991) acknowledge that these subordinate dimensions are related to big 5 categories; for instance, neuroticism and negative affectivity correlate with the distress scale and conscientiousness with Restraint subscales, impulse control and responsibility. But they suggest that their measure that focuses on social and emotional adjustment has the ability to increase understandings of personality and will improve on the prediction of adjustment.

Proposal of typologies

Weinberger and Schwarz (1991) propose the following typologies based on distress and restraint patterns:

- a) Reactive: high distress, low restraint
- b) Sensitised: High distress and low restraint
- c) Oversocialised: High distress and high restraint
- d) Undersocialised: Low distress and Low Restraint

e) Self-Assured: Low distress and moderate restraint

f) Repressive: Low distress and high restraint

In such an approach, rather than conceiving as distress and restraint as dimensions, and assessing for distress x restraint interactions, the analyses are performed for the aforementioned categorised using Analysis of Variance with respect to a range of outcomes relevant to physical and mental adjustment. Significant differences identified as group differences with respect to the outcome variables are interpreted as indicating that these states are associated predominantly with one typology versus another. According to Weinberger and Schwartz's (1990) analysis, the oversocialised followed by the repressive styles showed the poorest physical health whereas the self-assured (i.e. low distress and moderate restraint) showed the best physical health.

Further distinctions proposed

According to Garrsen (2007) the distinction between what he labels emotional defensiveness [i.e. labelled by Weinberger and Schwartz (1991) as 'oversocialised'] is helpful. For instance, Garrsen (2007) suggests that a broader term of defensiveness might subsume the two categories of over-socialised and repressive. Whilst both personality styles are presumed to be high in defensiveness, they would differ in the extent to which they report experiencing distress. Garrsen (2007) also proposes a further distinction and suggests that measures such as the LDMI Rationality subscale, and the emotional control scale measure personally related inhibition (i.e., general tendency to inhibit negative emotion) whereas measures such as the WAI measure socially related repression. In this form of repression, an individual shows a tendency to behave in socially accepted ways and/or in effort to win the approval of others (Garrsen, 2007).

Garssen's (2007) interpretation that Rationality is personally related construct and not socially related seems unlikely given that the majority of questions in the Rationality scale provide a frame of reference involving a social relationship. Nevertheless, Garssen (2007, p.480) does acknowledge that "future research will need to show whether relationships between questionnaires substantiate the similarities and differences between concepts described in this paper".

5.5.4 WAI: Summary

Garssen's (2007) approach to the issue of repression that attempts to distinguish it from other inhibition concepts whilst making conceptual sense, in some respects adds to the confusion already evident in the literature. The addition of new concepts that subsume other factors adds to the myriad of terms used with respect to the inhibition concept. In this study, the lack of correlations with other study variables was unexpected given the conceptual similarity implied in the literature.

Usefulness of typology perspective

The typology perspective appears useful as it provides an account of the repressive style, and typologies identified may help explain the inconsistent results concerning the inhibition of emotion on the one hand, and reports of distress on the other. This typology approach is also consistent with the earlier work conducted using different measures (i.e. Taylor's, 1953) Manifest Anxiety Scale and the Marlowe-Crowne Defensiveness scale; Crowne & Marlowe, 1964). The classification of individuals based on high/low distress and restraint into 6 categories has to be independently replicated. Nevertheless, some tentative evidence that this typology is useful has been reported by Giese-Davis, Sephton, Abercrombie, Duran and Spiegel (2004). They report that significant differences with respect to diurnal rhythms in women with metastatic breast cancer were shown when comparing the self-assured group with repressors. The authors of this paper also report that repressors showed evidence of cortisol dys-regulation.

5.6 Overall Summary

5.6.1 Overview

As reviewed in Chapter 4, the fundamental principle on which emotion focused therapies are based is the proposal that cancer patients under acknowledge/report distress. A fundamental component of emotion focused therapies then is to encourage individuals to express emotion, particularly emotions of a negative nature (anger, sadness). Such an approach is presumed to decrease distress, improve quality of life and, as heavily promoted by some researchers, ultimately impact on survival. As reviewed, measures of this kind of coping strategy (i.e. suppression/emotional control, repression, Type C) have been theoretically conceived with reference to Freudian concepts of ‘repression’ and ‘defence mechanism’ whereby individuals adopt a coping style that involves the inhibition and/or repression of negative affect.

Myriad of terms and a lack of application of contemporary theory

The major problem identified in the outset of the introduction presented in Chapter 4 was that a variety of terms are used to describe what appeared to be a relatively ubiquitous concept: ‘emotional inhibition’. In conducting an analysis that attempted to assess the degree of conceptual overlap among the various measures used to assess emotion regulatory strategies considerably more questions than answers emerged. The main limitations in this area appear to involve a lack of application of contemporary theory and a mismatch between stated theoretical propositions and concepts and the measures designed to assess them.

Suppression versus Repression

The results of this study indicate that Courtauld’s emotional control scale (CES: Watson & Greer, 1983) may provide the most valid and possibly direct measure of emotional inhibition. In contrast, the extent to which the LDMI measures the tendency to measure inhibit emotional responses appears to be limited to a few items that tap this construct. Some commentators

suggest that the CES measures the suppression of emotion which is conceived as a coping strategy potentially not as pervasive as repression (Giese-Davis & Spiegel, 2001). On an intuitive level this makes sense, however, from a conceptual and measurement level, scores on these measures should correlate because both measures purportedly measure the same tendency (e.g., the tendency to inhibit the expression of negative emotion).

For example, in terms of describing the ‘pervasiveness’ of one construct over the other it would be expected that repression would be conceived as a more enduring – and perhaps a trait - characteristic. In contrast, suppression would perhaps be conceived as less enduring - perhaps a state characteristic. Irrespective of the pervasiveness of the constructs, there should be some evidence of conceptual overlap. The fact that these measures, in factor analytic studies, appear to measure different constructs suggests that the WAI Restraint scale may not be measuring the inhibition of emotion. Alternative explanations then include that measures such as the WAI, and possibly other measures designed to assess repression, are measuring some other construct such as social desirability, and/or perhaps social adeptness. This finding would be consistent with Garseen’s (2007) proposal.

In summary, it appears that the concepts of repression and inhibition are similarly described yet the actual operationalisation of these concepts into measures has resulted in distinct constructs. It appears that the R/ED, LDM and CES do not all measure the same uni-dimensional construct.

5.6.2 Coping and Emotional Inhibition

As noted, a great deal of literature places the concept of emotional inhibition at the centre of inquiry when attempting to understand the coping strategies most prevalent in cancer populations. The focus of this literature has been on demonstrating links with certain regulatory styles and the development or recurrence of cancer. Despite decades of research, there appears to be no real evidence that demonstrates a definitive link with the presence or

absence of particular coping styles and the onset or recurrence of cancer. The extent, for example, to which these regulatory styles exist in general population samples (e.g., without chronic illness), appears to be under investigated. In those studies where data from cancer and general populations exist, the differences in supposed ‘cancer styles’ are not as clear as one would predict from suggestions made in the literature. In fact, it appears that suggesting that particular coping styles (e.g. ‘fighting spirit’) play a protective role in the recurrence of cancer, may place extraordinary pressure – and additional stress - on individuals to respond to a diagnosis of cancer in a prescribed and/or preferred style (Watson et al., 2001).

Unit of inquiry limited

Moreover, in focusing solely on emotional inhibition, the unit of inquiry has been limited to intrapsychic (i.e. individual) causes of maladaptive coping. Although Garssen (2007) uses the concepts of personally and socially related repression, emotion regulatory strategies are still conceived as stable and enduring personal characteristics. For example, there has been relatively little attention on the context and the environment within which the cancer patient experiences and/or copes with the day-to-day impediments faced following receiving a diagnosis of cancer. Research that focuses on concepts of inhibition and expression have failed to consider the receptiveness of patients’ social networks to engage in this style of communication.

The positive relationship reported between the emotional approach coping scales and social and family wellbeing may be particularly important in understanding the needs of cancer patients. For instance, a possible explanation for this finding could be that those individuals who acknowledge their distress and are able to express their feelings with family and friends ultimately report improved social and family wellbeing. In other words, perhaps the social and family wellbeing subscale of the FACT-G may be synonymous with an individual’s perception of their available social support.

5.6.3 Implications of Findings

Lack of support for theory regarding under reporting of distress

The major problem with interpreting the validity, and indeed reliability, of previous findings reporting on the impact of inhibition strategies on outcomes such as distress, mood and quality of life is that many of the results reported do not support the theoretical premises upon which the measures are based. As noted previously, in a recent critique published in the *Psychological Bulletin*, Pauls (2007) argues that an earlier meta-analysis (i.e., DeNeve & Cooper, 1998) that showed an inverse relationship between measures of repression and subjective well-being cannot be supported by theories of repression.

In terms of future research, it would assist if researchers explicitly stated how the findings related to theories of emotional inhibition (Garseen, 2007). As reviewed, Freudian theories of ‘defence mechanisms’ do not appear to account for the current findings. As noted previously cognitive accounts including Pennebaker’s (1997) account of inhibition as an active strategy particularly when conceived as a chronic stressor, may be useful. Furthermore, measures such as the emotional approach coping scale may prove useful in determining whether interventions involving ‘confrontation with stressors’ prove to be adaptive or maladaptive. For example, when considering the findings in the present study with respect to the EAC scale, the positive relationships with quality of life, in particular social and family well-being on the one hand, and distress on the other, may suggest that this measure is tapping an active attempt to process and/or express emotional material.

5.6.4 Caveats when assessing the efficacy of interventions

Given the conclusions reached, there are certain caveats that apply when assessing the effectiveness of interventions, and indeed research that assesses distress and/or quality of life in cancer samples. Although some reservations regarding the construct of repression have been noted during this discussion, the fact that over 50% of this sample met Weinberger and Davidson’s (1994) criteria to be classified as a repressor is a concern for the validity of the

findings reported thus far. For example, levels of distress and quality of life reported so far in this thesis have not been as severe as would have expected based on the literature that suggests that cancer patients experience significant psychological distress. For instance, if as the results suggest, over 50% of the current sample show a tendency to repressive negative affect, then the results reported thus far may seriously underestimate levels of distress experienced. Similarly, even if the Restraint scale is measuring a tendency to promote oneself favourably in social circumstances, as opposed to repression per se, then based on this tendency the results are still likely to be invalid.

Another issue requires consideration in terms of ultimately assessing the effectiveness of interventions with cancer participants, presumably high in repressive tendencies. What kind of outcome variable would be appropriate to assess the effectiveness of an emotion focused intervention? Theoretically, for example, an increase – rather than a decrease - in distress would indicate that a therapy has been effective. For example, an increase in distress and negative affect would suggest that the participant is acknowledging their distress (i.e. not repressing negative affect).

5.6.5 Limitations

Small sample

There are some limitations that pertain to the conclusions drawn in this chapter. The analyses presented in Chapter 4 were based on a small sample. Interpretations made concerning the conceptual and statistical overlaps among measures and the extent to which these measures predict quality of life and distress were limited in that several subscales were deleted due to low reliabilities. However, as reviewed some of the problems with the measures appear to reflect scale construction and similar findings may be observed when using large samples. Nevertheless, the small sample, and potential restriction of range on some variables, may have obscured the presence of some relationships. Furthermore, given that numerous bi-

variate correlations were performed, the potential for Type I error inflation cannot be excluded.

Effect sizes performed on larger samples

In contrast, judgements concerning the extent to which these measures discriminate cancer patients from non-cancer patients, were made on the basis of comparisons using larger samples (i.e. data used by authors during scale construction). Future research using more sophisticated analyses such as confirmatory factor analysis using programs such as LISREL, incorporating larger – and potentially more representative samples of cancer patients – and non-cancer patients is required. Such an approach may assist in identifying a latent factor involving ‘emotional inhibition’. Furthermore, the cancer participants in this study, for instance, appear to be particularly high in positivity (and repressive tendencies) which may be a function of the recruitment method.

Sample – repressors and volunteers

A related question then is to what extent do ‘repressors’ volunteer to participate in research that actively promotes a) emotional expression b) a need to reduce distress? As reviewed in the Appendix to Chapter 1 (see Appendix A), initial attempts at recruitment that specifically focused on emotional expression failed. However, when publicity was generated the journalist emphasised different approaches to coping with cancer. Many callers wanted to tell the researcher how well they coped with cancer. Some callers had their own theories, for example: ‘pets the best therapy’. Thus, perhaps unlike other studies where repressors may be unlikely to volunteer for participation in interventions that specifically focus on decreasing distress (i.e. repressors theoretically would not acknowledge that they are distressed), this sample may be over-represented by such individuals. Whether or not these participants are high in social desirability or actual repression however cannot be determined. Further assessment of the role of repression will be presented in Chapter 8 as part of an intervention

that applies Pennebaker's (1997) written disclosure method. In this chapter, possible differences between repressors and non-repressors following participating in an emotion-focused intervention will be described.

5.6.6 Conclusion

In conclusion, this chapter focused on attempting to understand the extent of overlap among measures typically used in previous research to assess coping styles and emotion regulatory strategies involving the concept of inhibition. Relatively little overlap on measures was evident leading to the conclusion that measures such as the CES and WAI appear to be measuring different constructs. Further research is required to determine the precise nature of these differences, particularly in terms of understanding the concept of emotional inhibition. This continued investigation is warranted given the emphasis of these concepts in the cancer coping literature and the focus in interventions designed to reduce distress in cancer patients.

Nevertheless, the focus on attempting to show links with certain individual characteristics and the development and/or recurrence of cancer has limited the knowledge that could be acquired concerning how patients cope with cancer. Adopting an approach that also considers the context within which participants experience and live with cancer may assist in developing more effective interventions and support systems for cancer patients.

6 A FOCUS ON COMMUNICATION AND PSYCHOSOCIAL SUPPORT: APPLICATION OF GROUNDED THEORY

6.1 Shifting the Unit of Analysis

In the cancer-coping literature, very little emphasis has been placed on the context within which cancer patients experience their illness. According to Engel's (1977) bio-psychosocial model, the interplay among psychological and social systems is important in both understanding and treating illness. In psychological research reviewed to date, it appears that efforts to develop knowledge concerning how patients cope with cancer have also been limited in scope, focusing predominantly on individual characteristics. Consequently, in terms of contributing to our understanding of coping processes, particularly in terms of providing effective coping support, this approach is limited. Furthermore, the interplay between individual and social aspects has not been adequately addressed. For example, individuals may have the ability and need to express emotion, but may not have the social resources to permit the expression of such emotion: Individuals within a patient's social network may not be receptive to communication that involves the expression of emotion. In terms of understanding the coping process, the importance of considering several units of analysis is emphasised by Hobfoll (2001)

...the encounter of the self with stress is primarily situated in social context or involving social consequence. This is not to say that the study of the self and even molecular study of the brain is invalid. On the contrary, they are rich avenues for study. However, the moment we are seduced into thinking that any one level is the primary active agent, we forestall the process and acquire scientific tendencies to guard the borders of our theories against the obvious veracity of broader perspectives.

Hobfoll, 2001, p.338-339

In this study, the major aim was to conduct an inquiry that also considered the context within which participants experience and live with cancer. When assessing whether patients describe

a need to express (or inhibit) emotion, the role of others in the patient's social network (family and friends) and wider network (i.e. health professionals and support services) is considered. Currently, such an account is not provided in the cancer literature. This approach may be important in terms of understanding previous research involving coping styles and the inhibition concept. This approach also appears valid in terms of potentially developing models of coping and support that could a) inform individual level interventions to reduce distress and improve quality of life, and b) inform community level interventions.

6.2 Methodological Approach

In this study, an exploratory and qualitative approach is adopted. Thus, the focus is on the generation of hypotheses. Principles of grounded theory (Glaser, 1992, 1978; Glaser & Strauss, 1967) are used to anchor the philosophical approach adopted towards the conduct of the research; the collection of data; the analysis and coding of responses; the development of models; and, the generation of theory. The grounded theory approach represents a significant philosophical departure from the traditional scientific approach (i.e. hypothetico-deductive) used in medicine and psychology. Thus, an overview of the approach and an account of the application of grounded theory to this study are provided. Grounded theory has been defined:

... as an inductive theory discovery methodology that allows the researcher to develop a theoretical account of the general features of the topic while simultaneously grounding the account in empirical observations of data.

Martin & Turner, 1986, p. 141

In grounded theory, inductive reasoning is used to propose hypotheses and develop theory according to observations made in data. The conduct of research, without specifically incorporating previous theory, as is the basic requirement of the grounded theory approach, represents a significant departure from mainstream scientific approaches. In hypothetico-deductive methods, deductive reasoning is applied when testing hypotheses derived from theory. According to Fernandez (2004), two major canons apply to approaches that claim to

incorporate principles and philosophies of grounded theory. Citing the work of Urquart (2001), Fernandez (2004, p. 45) suggests that the following two tenets of grounded theory are the fundamental building blocks upon which grounded theory approaches are based:

- 1) “the researcher has to set aside theoretical ideas; and,
- 2) the concepts are developed through constant comparison”.

Originally known as the constant comparative method, grounded theory was first developed by Glaser and Strauss (1967). The constant comparative method refers to the research process where everything is integrated and whereby all data, and observations made, are constantly compared until a theory emerges (Fernandez, 2004). Citing the early work of Glaser and Strauss (1967), Fernandez (2004, p 45) suggests that:

The constant comparative method facilitates the generation of complex theories of process, sequence, and change pertaining to organisations, positions, and social interaction that correspond closely to the data since the constant comparison forces the analyst to consider much diversity in the data.

Disagreement between authors, Glaser and Strauss resulted in the publication of slightly different approaches (e.g., Glaser, 1992; Glaser, 1978; Strauss & Corbin, 1990); these approaches tend to be referred to as the Glaserian and Straussian approaches (Stern, 1994). According to Fernandez (2004), the emphasis on conceptualisation versus description is at the core of the debate between Glaser and Strauss. Fernandez (2004) suggests that the Straussian approach is more suitable for descriptive accounts, whereas the Glaserian approach is more suited to the development of conceptual knowledge. Walker and Myrick (2006) provide a detailed description of the differences inherent in both approaches and suggest that the major difference occurs because of the different procedures used to analyse the data.

In both accounts of the data analysis process, both begin the analysis by describing the data (open coding) and include stages relevant to ordering and categorising the data conceptually (i.e. inferring relationships among categories) and conceptual ordering (theoretical coding). Within the Glaserian approach, data are allowed to emerge into theoretical categories whereas in the Straussian approach (due to the prescribed nature of the analysis) the data are forced into codes reflective of particular paradigmatic emphases (Walker & Myrick, 2006). For instance, Strauss and Corbin (1990) propose a complex coding system that assigns data into particular 'paradigmatic' codes such as: phenomena/context, intervening conditions, action strategies, consequences (Fernandez, 2004).

In Glaser's (1992) view, such an approach may interfere with the research and inductive processes by forcing data into preconceived codes. Glaser (1992) proposes an approach involving 2 stages of coding: substantive coding and theoretical coding. Substantive coding consists of 2 sub phases: open and/or selective coding. Open coding refers to opening up the data to as many codes as possible and describing the data and its properties (Glaser, 1978). Selective coding refers to the emergence of patterns in the data, which may involve a reduction in the number of codes, or the collapsing of many codes¹⁵ observed in open coding. Substantive coding (whether open or selective) is focused on producing codes and describing their properties. Theoretical coding occurs at a higher level (i.e. conceptual level) and is where the substantive codes (i.e. higher order categories) and the relationships among them are worked forward into producing hypotheses and theory.

Central to Glaser's (1992) emphasis is that following open coding, and with constant comparison of data, theoretical codes will emerge allowing for the development of theory. In other words, Glaser's (1992) view is that the dimensional aspects (i.e. relationships among

¹⁵ In commentary concerning the grounded theory approach the terms codes and categories are used interchangeably. Although coding refers to the act of placing data into categories, the emerging categories are still referred to as 'codes' – sometimes these codes are called 'core codes'.

categories), will emerge ‘naturally’ because of constant comparison that occurs during substantive coding.

6.3 Application of the Grounded Theory in this Study

In this study, the Glaserian (1992) approach to the conduct of analysis will be incorporated. Based on literature and commentary describing the differences between the Glaserian and Straussian approaches, it appears that this approach is less restrictive and least aligned to a particular paradigm of inquiry. The codes such as phenomena/context, intervening conditions, action strategies and consequences do not appear to have any specific relevance to the current study. Thus, forcing the data into these preconceived codes would appear to limit the generation of applicable and relevant theory.

Furthermore, within the Glaserian model, the approach to data analysis (i.e. coding) is aligned with a focus on conceptualisation as opposed to description. At this point in the thesis, a need for conceptualisation rather than description exists. For example, the overall aim in this thesis is to work towards the development of effective strategies to manage chronic illness, and thus far the conceptualisations offered in the literature have not been validated by data. In addition, the Glaserian approach presents a more inclusive approach to the range of data sources that can be legitimately incorporated into a grounded theory approach. For instance, within the context of this thesis previous research and findings (i.e. observations noted by the researcher in this thesis) with respect to substantive areas of interest (i.e. improving the management of chronic illness) can be incorporated into theories generated using the grounded theory approach (Fernandez, 2004).

Figure 5 shows the typical research process using a Glaserian approach to grounded theory (Fernandez, 2004). After entering the field (step 1), each part of the data collection process can be understood as gaining a ‘slice’ of data relevant to the substantive area of interest. Although these ‘slices’ typically refer to data collected from one research participant, these

slices can also be understood as comprising ‘slices’ of knowledge gained throughout the entire research process.

NOTE:

This figure is included on page 175 of the print copy of the thesis held in the University of Adelaide Library.

FIGURE 5

Glaserian Approach to Grounded Theory (Fernandez, 2004)

Permission to reproduce this figure was gained from the Australian National University

The main substantive area of inquiry in this thesis is improving the management of chronic illness. Within this substantive area, several slices of data have been assessed in terms of their ability to inform the development of effective strategies to manage chronic illness. But after considering several ‘slices’ of data, an incomplete account of the data was provided by existing theory relevant to coping processes in cancer populations.

In other words, incorporating the terminology of grounded theory, current theory concerning the inhibition concept and cancer coping styles provided a poor fit with the data presented to date. Moreover, the focus on intrapsychic causes of emotional inhibition appeared to be limited in terms of its ability to generate useful and testable hypotheses, and lacked utility in terms of informing the generation of interventions that could be used to assist patients cope

with cancer. Again, incorporating the terminology of grounded theory, theoretical saturation (see Figure 4) had not occurred.

The researcher achieves theoretical saturation when the main concern of the research can be accounted for, and further sampling fails to add significant value to the study through adding new categories or properties.

Fernandez, 2004, p. 51

Thus, in returning to sample additional slices of data the theoretical sampling frame in this study shifted.

Theoretical Sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyses his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges. This process of data collection is controlled by the emerging theory, whether substantive or formal

Glaser & Strauss, 1967, p. 45

6.4 Summary and Review of Aims

The unit of analysis in this chapter has shifted from a purely individual focus to one that also incorporates the patient's social network. This unit of analysis was chosen on the basis of observations made by the researcher thus far. For example, in further exploring the role of emotional expression/inhibition, an understanding of an individuals' social network and their receptivity to this form of communication might provide additional knowledge. The particular sampling domain chosen to assess the interplay among individual and social factors principally focused on communication and support services. For example, despite the availability of support services and provision for referral to psychologists within major hospitals, previous research suggests that a 'lack of need' is associated with low levels of

utilisation of support services (Jefford, Black, Grogan, Yeoman, White, Akkerman & 2005; Pascoe, Edelman & Kidman, 2000).

Considering data focused on the perspective of communication and support experiences may provide insight into understanding whether a lack of need is linked with low levels of utilisation. Or, perhaps, as is suggested by critics of the biomedical model, the current focus on symptoms, rather than the whole person's needs, may lead to a lack of emphasis on emotional aspects of the illness resulting in a lack of referral to services. Furthermore, a focus on communication and social support, was judged to be a potentially rich avenue of data with respect to providing further insight into domains of interest that existed at the commencement of this thesis (e.g., understanding the nature and extent of disability experienced as a result of chronic illness), and have emerged in this thesis (e.g., emotional inhibition). This focus may also shed light on the acceptability and relevance of processes such as shared decision making, multi-disciplinary approaches (i.e. shared care), and holistic models of care.

In summary, the grounded theory approach, particularly as described by Glaser (1982, 1992) and others (Fernandez, 2004) is particularly useful at this stage in the current research process. Attempts to apply current theory have not provided an adequate account of the empirical data presented thus far. In this chapter, the results of the first stage of the analysis (i.e. open and selective coding) are presented. In Chapter 7, theoretical coding occurs and the literature is consulted for its completeness in terms of providing an account of the data emerging from this study.

The aim when developing substantive theory was to develop a) generate hypotheses concerning the coping processes in cancer patients; and b) inform individual and community level interventions designed to reduce distress and improve quality of life. Furthermore, an attempt to ground the development of theory, not only with the data, but also with the

participants providing the data, was made. For instance, in ensuring that the results represent a valid account of patients' experiences, and as part of the constant comparison process, participants were involved in validating the coding process and the proposal of recommendations. As noted in Chapter 1, this methodological approach assists in reducing researcher bias.

For example, this approach was consistent with qualitative research approaches where efforts are made to validate the data (Meyrick, 2006) and with the Participatory Action Research paradigm (PAR; Elden & Chisholm, 1994; Kemmis & McTaggart, 2005; Susman & Evered, 1978), where participants are encouraged to be active participants in the research process. Current commentary in health psychology and health policy, for instance, suggests that in developing effective health care models, consultation with patients (as opposed to expert medical professionals) is crucial when attempting to develop high quality health care (Meyrick, 2006).

6.5 Method

6.5.1 Participants and Sample

As described in Chapter 1, twenty participants (13 female and 7 male) were recruited via publicity generated by the University of Adelaide's marketing and communications department. Information pertaining to selection and exclusion criteria were reviewed in Chapter 1.

Participants ranged in age from 44 to 73 (M , 58.35, SD , 8.20). Time since diagnosis ranged from 6 months to 156 months (i.e. 13 years). The mean time since diagnosis was 47.9 months (SD = 41.32). The majority of patients were in remission (N = 16); one patient was currently receiving treatment for a recent diagnosis; two patients had a diagnosis of recurrence and were receiving treatment; and one patient was not in remission. This participant was not

receiving treatment at the time the interview was conducted. As shown in Table 24, patients had a variety of diagnoses.

TABLE 24
Types of Cancer Diagnoses (N = 20)

<i>Diagnosis</i>	<i>N</i>
Acute myeloid leukaemia	1
Breast	5
Colorectal	3
Head and Neck	3
Lung	1
Lymphoma	1
Non Hodgkin's Lymphoma	2
Prostate	2
Stomach	1
Testicular	1

6.5.2 Measures

Research interview

Participants were interviewed using a semi-structured interview. Although the researcher had specific questions in mind when conducting this study (i.e. as per the substantive areas of inquiry in this thesis), these were not made apparent to the interviewees. Questions focused predominantly on the domains of communication and support. Additional questions also focused on treatment, patient expectations, emotional expression, and recommendations.

In ensuring that the researcher did not impose prior beliefs on the research process, questions were deliberately open ended and of a general nature. Questions included: “How would you describe the communication you had with medical professionals during your illness?”; “How would you describe the communication you had with family and friends during your illness?”; “In terms of your experience with your doctors, were your expectations met?”; “How about your treatment, do you think things could’ve been done differently?”; “Were you satisfied

with the treatment options provided to you?"; "Did you have the opportunity to express how you were feeling to anyone?" Questions also sought to assess the willingness of participants to be involved in an intervention involving the expression of emotion. A copy of the interview schedule is provided in Appendix G.

During the interviews, an unstructured approach was implemented when it was necessary to explore issues that participants had identified as relevant and meaningful during the evolving conversation. For instance, the ordering of the questions while followed generally, was sometimes amended to facilitate a more fluent and information rich conversation. For instance, some patients entered the interview by discussing issues that were relevant to questions asked later in the interview.

Clinical interview

To complement the research interview questions that included a focus on the uptake of support services, participants were interviewed using the Mini-International Neuropsychiatric Interview (M.I.N.I., Sheehan et al., 1992) to assess for Axis 1, DSM-IV diagnoses. As discussed in Appendix A, three participants were assessed using the Structured Clinical Interview (Spitzer, Gibbon Williams, 2002), however, due to participant burden, this measure was deleted and was replaced with the M.I.N.I.

6.5.3 Procedure

Timing of assessments

The majority of participants completed the screening interview, the clinical interview, and the research interview on one occasion. The time taken to complete these interviews varied considerably between participants. Completion of the screening and clinical interview lasted on average 1 hour. The research interview lasted between 1 and 2 hours. The average duration was 50 minutes. The majority of participants were interviewed in the researcher's office located at the University of Adelaide. Five participants were interviewed in their

homes, or at their place of employment. The majority of participants were interviewed by themselves, however, in one interview, a marital partner was also present.

All interviews were recorded on audio-tape, and transcribed. Tapes were periodically transcribed to ensure that the questions were eliciting information rich responses.

Furthermore, the transcription of interviews at periodic intervals enabled the researcher to ensure that the codes emerging from the analysis were reflective of patients' experiences of illness. This method facilitates a focus on the data and thus codes and theory were based on the data and were not based on the researchers prior beliefs about what should be found.

Coding approach

Consistent with Glaser's (1992) approach, data were open-coded to enable the detection of as many codes as possible. The focus was not on reducing patient responses to a few categories, but rather a broad approach was taken that incorporated exceptions to frequent, or dominant responses. Within this open-coding phase, some selective coding was also conducted. For instance, as uniformities were detected in the data, additional codes were added, and some codes were collapsed or re-ordered. The results of this stage of coding are presented in this chapter. To ensure that the results were void of researcher bias, the data were subjected to elaboration, confirmation and/or contradiction when the codes were presented to research members (i.e. consistent with the PAR approach). Exceptions and contradictions highlighted by research members resulted in the generation of new data that were then subjected to further analysis.

In the second stage of analysis, the researcher began theoretical coding and codes were collapsed into higher order codes. At this point, relationships among codes within the major substantive areas that emerged were developed and hypotheses proposed. Within this analysis and when working towards the development of theory and recommendations, the degree to

which existing literature provided a complete account of the data (including contradictions) was assessed. The results of these analyses are presented in the next chapter of the thesis.

Participant involvement in coding and the proposal of recommendations

Approximately nine months following the initial interviews, participants were invited to provide comment on the results in terms of their relevance and applicability to their experiences. Because the results indicated that patients generally had negative attitudes towards support groups (see later in this Chapter), participants were given the option of attending a group session (i.e. an information session held at the University of Adelaide), or an individual session. Five participants attended the group session with the researcher acting as the facilitator. A further five participants attended an individual session held by the researcher.

After the researcher presented the findings, participants were asked to comment on the relevance and applicability of the results. Participants were also encouraged to challenge the coding and provide new or contradictory information. Finally, participants were asked to workshop the findings and develop recommendations (either from existing data) or new experiences that had occurred since the first interview. These sessions were not recorded and instead the researcher recorded patients' responses in a verbatim manner using short-hand when necessary.

6.6 Results Clinical Interview

Table 25 shows the results of the clinical interviews performed with patients. Of the probable diagnoses shown in Table 25 most were pre-existing; that is the onset of the psychological disorder occurred prior to the onset of cancer. One of these diagnoses (i.e. psychosis) was temporary and not present at the time of the interview. According to this participant, the psychosis occurred as a direct result of the cancer treatment and resulted in her being

hospitalised. In 3 cases, the psychological disorders did occur following the experience of cancer. In two cases, the diagnosis was dysthymia and in the third the diagnosis was social phobia. None of these participants had been offered or received any psychological or counselling support. Of those with existing conditions, one participant was under the long term care of a psychiatrist, whereas others had medicine prescribed for their conditions by general practitioners. Only one patient had received recent formal psychological treatment for their psychological condition, although one participant reported seeing a psychologist at the first onset of depression (e.g., 5 years ago).

Also shown in Table 25 are those participants that reported being exposed to a traumatic event. These events ranged in type and when participants were recounting their experiences, not a single participant identified receiving a diagnosis of cancer as a traumatic event during the clinical interview¹⁶. Instead, events referred to natural disasters (e.g., a cyclone), a near shark attack, being robbed/mugged or other violent incidents. One participant reported a history of child abuse.

TABLE 25
Results of Clinical Interview: Diagnoses According to the MINI (N= 20)

<i>Diagnoses according to the MINI</i>	<i>Number meeting Criteria</i>
Social phobia	2
Dysthymia	2
Bipolar Disorder	2
Panic Disorder	1
Depression/Anxiety	1
PTSD	1
Psychosis	1
Exposure to traumatic event	15

¹⁶ Two participants described cancer as a traumatic experience during the research interview, however, during the clinical interview when asked: Have you ever experienced or witnessed or had to deal with an extremely traumatic event that included actual or threatened death or serious injury to you or someone else, one answered no and the other provided an account of another traumatic experience.

6.7 Results: Substantive Coding

Shown as follows are the results of the first stage of analysis. As per Glaser's (1992) approach, this included a combination of open and selective coding.

6.7.1 Substantive Code 1: Unsuccessful Coping Efforts

(i) Coping through talking – but efforts fail

Participants frequently described efforts that involved attempts to cope through talking. As evident in the following response these efforts did not result in patients receiving the support that they were seeking.

The way I coped with it was to tell everybody what was happening. People I'd worked with for years and see them in the snack bar and they'd look the other way. Felt uncomfortable because [sic] didn't know what to do. You end up being a counsellor for all of these other people. Women turned the other way. They were so uncomfortable so I'd end up trying to make them feel better.

[Female: Breast]

(ii) Others do not have the capabilities

In reflecting on the cancer experience, a participant noted that others in his social network appeared to lack the skills and capabilities to know how to deal with communication concerning cancer, although this participant believed that close friends and females were more equipped.

I am open to anyone who wants to talk about it but people don't want to know, or don't know what to say. Males can't handle it. True friends and females more equipped.

[Male: Head and Neck]

(iii) Avoidance and superficial communication

Participants noted that others in their social network coped with cancer by using strategies such as denial, or shifted the conversation towards superficial matters (e.g., sport and the weather). Although, there were individual differences in the manner in which others responded to cancer:

Some of them are very supportive and some of them just want to avoid it. My father doesn't want to know about it, he'll politely ask how I'm feeling and as long as I say I'm fine then that's alright.

[Female: Lymphoma]

Others believed that individuals in their social network avoided asking how they were really feeling and/or did not ask how they could help.

They didn't want to talk about it but I did. Not in a morbid way but I just wanted to say how I was feeling and you know the pain and the all of the terrible things that went along with the surgery, and the radiotherapy, that experience you know. I wanted to write a book like, 'The Road Less Travelled' and I thought yes I guess not many people go through this. And if they do, they don't survive. And people I don't think wanted to, they talk about the weather or the footy and things like that but didn't want to say really how are you feeling? How can we help?

[Male: Head and Neck]

(iv) Sense of vulnerability

One participant ascribed this lack of wanting to communicate about cancer due to others feeling vulnerable to cancer. "Because they don't know how do deal with the cancer. Makes them vulnerable, it could be me" [Female: Stomach].

(v) Interpersonal tension

Other participants described interpersonal difficulties and or tension that occurred. This tension appeared to be linked with expectations that patients had concerning the kinds of

supports a partner might offer but that due to a lack of understanding, that support was not forthcoming.

My communication with my husband was not good. It took him two weeks to ask me which breast it was. Came to a head for a while for a few weeks but then things were much better and returned to normal. I think I was looking for things from him which he just didn't understand.

[Female: Breast]

(vi) Lack of understanding – distance in relationships

At times there appeared to be a certain amount of distance between the patient and their family. This seemed to occur as a result of a lack of understanding of each other's perspectives. A head and neck patient who had been in remission for 5 years had experienced a diagnosis of recurrence. He was clinically depressed and was receiving medication for his depression. He said that he tried to communicate with his wife and children but that they just did not understand and that his wife's response to his depression was unhelpful. This participant also acknowledged that he did not understand what his family members were going through.

I try to talk to my wife but she blames the drugs and says get off them. I'm trying to talk to sons, wife but they're not listening. I don't know what they're going through and they don't know what I'm going through.

[Male: Head and Neck]

(vii) Providing support to others

Others noted how during their illness that they needed to expend personal resources on supporting others who were not coping with them having cancer. One participant said that her "... immediate partner was devastated. He said they'd made a mistake. He cried. I supported him heavily" [Female: Breast]. Though support was forthcoming from family members if they had a personal experience of cancer: "Pretty bloody hard. Young son okay, other two cracked up. Son had testicular cancer. He knew what I was going through" [Male: Lung].

(viii) Dishonest communication and putting on a brave face

Some patients acknowledged that their communication with family and friends was not always truthful. It was apparent that patients were, in many cases, describing the need to put on a brave face (i.e. positive spirit) to assist others cope/adjust to the participant's diagnosis of cancer. Participants generally felt that if they were honest in their communications (i.e. said how they were really feeling) this would cause others to be distressed and/or others would not know how to respond.

Others noted that concepts such as positivity are put forward by others as successful ways to cope, and potentially 'cure' cancer. As evident in the following patient's comment, these beliefs result in some annoyance, and are possibly more relevant to those who do not have cancer.

You know people always say to me, you know because I've got a pretty positive attitude, your positive attitude is what will get you through, and I say to them, have you ever read the death columns? It's full of people with positive attitudes. And you know I said to someone the other day that a positive attitude probably makes it better for everyone else right because it is not going to save your life, it might help you cope with dying a bit easier, and makes it easier for all other people. I mean look at Belinda Emmett [Australian television celebrity] what a positive attitude - but she died. I don't think you should be negative but positivity is not going to save your life.

[Female: Breast]

6.7.2 Substantive Code 2: Successful coping efforts

(i) Honest communication with similar others

Few responses involved the reporting of positive accounts of coping through communication. Exceptions involved instances whereby patients had the opportunity to talk to others with

cancer. In this study, these opportunities occurred as a result of chance meetings rather than being facilitated by formal services (e.g., programs such as the Cancer Council's Connect program). Opportunities to meet with similar others were highly valued. In such instances, participants were able to be honest in their communication and felt understood.

Work colleague of my husband's in [hospital] waiting for a stem cell transplant. I went down and I'd never met this guy before and we sat and talked for my whole lunch hour and said things you can't say to other people. He knew what I felt, and I knew what he felt. He died. But he would've been one of the few people that I could really say how I feel.

[Female: Breast]

Another participant reported that he appreciated the social contact with similar others that was informally facilitated; for example, he described his experience whilst sitting in the waiting room during his course of radiotherapy treatment.

I think in reality the sitting in the waiting room for radiotherapy at ... was a good experience because had a chance to speak to other people, not so much for me but I was interested in hearing their stories and giving them some positives. It was a good social thing because at that point I wasn't having much social contact and I really craved it.

[Male: Head and Neck]

(ii) Religion and spirituality

Some participants linked spirituality or religion with positive accounts of coping with cancer. These accounts were relatively infrequent across the entire sample, but the true extent of participants' beliefs may not be realised in this, and potentially other studies. For instance, when one participant was describing his religious involvement, he asked the researcher to turn off the tape, as he was not sure if it was something that the researcher would be interested.

For some participants these experiences appeared important in terms of describing their experiences with cancer. In this sample, more participants mentioned spirituality than religion.

When describing religious involvement some linked positive experiences with psychosocial aspects involving support; for example, others praying for, opportunity to talk with others who were receptive. Beliefs in religion appeared to extend beyond issues of communication and were associated with concepts such as strength, peace, comfort, acceptance of the cancer and preparation for death. In the following comment, a participant noted these concepts and also declared that, for him, cancer was a 'brilliant experience'. This participant also said that due to his beliefs and experiences he did not need to seek support elsewhere.

Strong belief in religion – prepared by my thoughts and death, not in morbid way. In surgery, expecting that probably cancer, comforted because if God had a purpose for me on this earth then I'd be here. If he didn't, then it's gotta be better than this life. So I didn't need any support. I did tell everyone who would listen. It was a brilliant experience for me. That peace and comfortedness.

[Male: Colorectal]

Descriptions of spirituality were defined more broadly and were linked with a variety of concepts, including the universe, engagement in certain practices such as meditation or reiki, being on the same wave-length as others, and openness to view issues from multiple perspectives. For instance, a participant when describing her interaction with her son and a friend said:

He knows what I'm talking about spiritually and for some reason we're on the same plane. And I could talk to him in that way and that was important to me. My psychologist friend also spiritual. Those people very important to me. When you're on a spiritual plane you have a better chance of looking at things from different aspects.

[Female: Breast]

Spiritual experiences tended to be described in terms of positive growth experiences that in some way transformed individuals' attitudes. As follows, a participant describes, within a spiritual context, how she was able to overcome her losses and focus on her resources.

What you can do is stop focusing on your losses and focus on what you can do and what you can create. Work things out and problem solve. Can't carry in the garden but can use a trolley – I thought yes, and I think this is like a spiritual journey– if you start on a journey where you start doing things then things start coming your way.

[Female: Stomach]

(iii) Alternative therapies

There were incidences whereby patients reported positive coping experiences, particularly in terms of gaining social support from engaging in alternative therapies. For instance, a male patient who received vitamin C infusions during his radiotherapy treatment reported enjoying 'bonding time' with an old friend who also had cancer, and also with his general practitioner who was reportedly trained in naturopathy.

Yeah, yeah, well he was seeing other patients while infusions happening. Interesting thing that happened when I was there is that a friend of mine ... also and [sic] having done same time. [He was] a joker. And [GP] used to come in after every patient. Really helped good bonding time.

[Male: Head and Neck]

Another patient who was very emotional during the interview noted that she gained a sense of support from attending massage appointments with an alternative therapist. In this instance, this appeared to be linked to 'talking' with the therapist about others who also had been through the cancer experience.

But I still didn't identify myself as needing to go and talk in a group situation. I guess been having massage – lymph – because most her clients have had cancer – find useful to talk to her.

[Female: Breast]

6.7.3 Substantive Code 3: Treatment Experiences

(i) Positive account of treatment

Overall patients provided a positive account of their treatment experiences to the researcher. For instance, some patients reported on their treatment experiences as if they had very little impact on their lives. Some continued to engage in work, and participate in their usual leisure activities.

(ii) Side effects and self-focus

Participants were asked about the side effects of treatment and whether or not they had received adequate information concerning these. Many patients appeared not to be aware of any side effects, or reported that those experienced dissipated quickly. These patients tended to present a positive account of their coping with treatment to the researcher and focused on how they continued to work. Others who did report considerable side effects reported being extremely focused on themselves during the treatment process and reported the need to conserve their resources for use in coping with the treatment.

I think [sic] wasn't connected to what was going on around me as much as I usually did– you seem to withdraw into your own little shell because you have to deal with yourself. Not really interested in that mess over there, or the dishes aren't done. In away you protect yourself, because you have to withdraw your energy.

[Female: Non-Hodgkin's Lymphoma]

(iii) Sense of accomplishment – badges of honour

Many described their treatment experiences with a sense of accomplishment and one participant reported a sense of pride and saw scars and changes in physical appearance as ‘badges of honour’.

The plastics guy who was doing the reconstruction, a year after the operation he apologised to me, and like I said I did look like Frankenstein. He said when he did the reconstruction of the soft palate it was text book but when I sewed you up afterwards it was like Christmas turkey because we didn’t expect that you would live. I’ll do it free of charge and I said no this is like a badge of honour and I’ve got a beard now so not so obvious.

[Male: Head and Neck]

(iv) Health professionals underestimate side effects

Most participants were happy with the information provided to them concerning potential side effects of treatment. However, some participants thought that the extent of the side effects, and ongoing consequences of the treatment were not adequately described, or that the information did not truly reflect the severity of the symptoms experienced. As described in the following comment, one patient did acknowledge that sometimes more information may not be the best method of dealing with this issue.

More should’ve been said about that. I think they should tell you a bit more. They say, you may feel sick, or you may do this; they should tell you that you can feel really rotten because you don’t know how far you can go. They tell you if your temperature so and so then you need to go to hospital. But they should tell you a little more but maybe they don’t want to put those ideas into your head.

[Female: Breast]

(v) Dissatisfaction with the management of ongoing issues

Others discussed ongoing issues with conditions they believed were directly related to their treatment. Many reported dissatisfaction with the management of these issues.

... when you've reached end of treatment, or remission, there's no one that picks it up. It all just falls away. You're well go home. I think there could be a bit gap there and there could be an opportunity for people to get together and manage that treatment. My oncologist lovely but he's done his job and it's like well you can go on and live your life but no one is managing those daily things like the fatigue, irritable bowel, getting back into the workforce if that's what you want to do.

[Female: Non-Hodgkin's Lymphoma]

Examples of ongoing issues reported included: Early onset of menopause, migraine, vision, irritable bowel, osteoporosis, memory (particularly short term or working memory – “foggy brain”) sleeping difficulties (particularly awaking in the night), hot flushes, panic attacks, claustrophobia, and increased emotional sensitivity.

A male with lung cancer commented: “ ... get more emotional now, watching television – kick you in the guts quicker. Put down to the chemo” [Male: Lung].

(vi) Not dissatisfied with the lack of participation in decision making

Patients were asked whether they were satisfied with their treatment options. In retrospect, the researcher realises that this was a biased question because the researcher had presumed that patients would have been provided with treatment options. In this sample, all excepting one patient said that they were not provided with treatment options. Examples of some comments included:

Didn't really get any [treatment options]. You really have to do this [Female: Breast]; I think they perceive that that's the right treatment for you [Female: Breast]; I wasn't given options just told what we'll be doing next. You want to do what you need to do [Female: Lymphoma].

Overall, patients did not appear to be unhappy with not being provided with options concerning their treatment. They believed that doctors know “that’s the right treatment for you” [Female: Breast] and knew the appropriate “steps you have to take” [Female: Breast]¹⁷.

Others also perceived that involvement in decisions concerning treatment were outside of their knowledge. For example, when a participant was asked if she was satisfied with the treatment options she had been provided with, she responded: “Don’t know because I haven’t had enough experience to really know” [Female: Lymphoma]. Another participant commented: “And what does the layman know, you just go with it” [Female: Breast].

One participant noted that she was not happy with the options provided to her. Though this dissatisfaction appeared to be linked with her retrospectively linking particular side effects with the treatment she received.

... I questioned the lumbar puncture, questioned the effect of the chemo on the brain. It’s standard part of the treatment and you have to have it. My feeling was that maybe I didn’t need it. But you’ve got to go along with what they say. Left me with a foggy head is probably the best way to describe it. I feel like passing out, you know if I get anxious so it has effected my health.

[Female: Lymphoma].

(vii) Perception that more options in the private system

Another patient noted that if his personal situation was different (i.e. if he had more money) that he would have explored options overseas and perceived that if he had of been treated in the private system, instead of the public system, then he would have been given more options.

¹⁷ In reality, there may not be as many treatment options as the researcher had envisaged. The decision may not be one of receiving chemotherapy or radiotherapy, but instead may involve which particular chemotherapy will be most effective. In such situations, the decision would be made by the oncologist and would be based on empirical evidence. In these situations, the patient would not have the specialist knowledge to decide which particular chemotherapy should be used.

If you get a private doctor, he can do what ever he likes. Seems to be a regiment of treatment at [public hospital] ... One reports for treatment, I read in the book – all stick by their treatment – I think should have an introduction to the three and then make a decision¹⁸.

[Male: Prostate cancer]

(viii) Provision of options linked with perceptions of control

Provision of options in the one patient who reported it, appeared to be associated with a sense of acceptance and/or potentially a sense of control over the surgery and recovery process.

I think the positive thing about this is that I chose what would happen I didn't sort of say well you're the experts I'm in your hands and you do what you think is necessary. I think a bit part of, maybe even so far [sic] my successful battle with this terminal illness is that I owned it I took it on board and said ok this is mine and I have to think of a way to deal with it. I even looked on the Internet, even thought of going overseas like Mexico and some other places like that to get treatment but in the end I chose the treatment and I told the doctors that too.

[Male: Head and Neck]

(ix) Urgency to begin treatment

Rather than having a need to participate in decision making, patients' most critical concern was related to the timing of the treatment (e.g., Let's do this and it's gonna get done now [Male: Lung]. Another participant commented that the treatment "probably could've been quicker" [Male: Bowel] and another stated that he was "anxious for the treatment to start as soon as possible" [Male: Testicular].

6.7.4 Substantive Code 4: Nature of Psychosocial Support Received

(i) Emphasis on practical support during treatment

In describing communication experiences with friends and family, patients frequently noted their appreciation for friends and family who were extremely supportive in terms of assisting

¹⁸ This participant was referring to 3 treatments used: surgery, hormone therapy, and radiotherapy

with practical things. This generally occurred when patients were undergoing treatment such as chemotherapy or radiotherapy. Assistance with running the household was provided such as washing, cooking, picking up children.

(ii) Finish of treatment – all support withdrawn

Frequently, participants described their disappointment with others in their social network at the end of formal treatment. For instance, a patient noted that during therapy some friends were loving and caring but that others perceived that all was well once the therapy was finished: “Some of them when having therapy very caring and loving but once the therapy has finished you’re all fine now, and I’m not all fine” [Female: Lymphoma].

(iii) Communication stops

Many expressed a sense that all communication stopped, and support was lost at the end of formal treatment. It appears that participants are at risk of experiencing considerable distress at this time. Participants reported experiencing a range of emotions (sadness, anger, frustration, isolation) and physical exhaustion. For example, some participants reported being overwhelmed with fatigue and reported that they just could not cope as they had previously (i.e. prior to cancer).

Yet others in their social network appeared to expect that following the cessation of treatment that they would return to their former selves and would engage in the same activities and fulfill the same roles as before. As shown in the following comment, others in patients’ social networks appear to judge patients if they did not return to their former selves.

When I stopped treatment, and everyone thinks well you’re okay now. And the phone calls stop, and you’re left at home and you’re left with the tiredness.... People just look at you and think why aren’t you back at work and then the anger started because of the frustration. You can only tell people so many times that you’re tired. People see that

you look well so they expect a lot of you and that is a frustration – becomes a really big issue. I know [sic] have to pace myself. She looks okay why isn't she doing things. Becomes isolating.

[Female: Non-Hodgkin's Lymphoma]

Others also described support that occurred earlier in the process yet they could not understand why this had stopped. When specifically asked if he was satisfied with the support he received, a participant commented on the support he had received prior to his operation.

Initially, I would've said great as had a lot of church support and people praying for me all around the world. Australia and in England and America so that was great. Lots of friends, lots of support, family huge support. But after the operation and after radiotherapy it was like something happened and I don't know what it was.

[Male: Head and Neck]

6.7.5 Substantive Code 5: Uptake of Support Services

(i) Lack of uptake of services

The results indicated that 3/20 participants made use of established support services: One participant had been involved with the "Life after Cancer" program with the Cancer Council, 1 one had received counselling services and massage via services offered at the Cancer Centre, and one participant reported ringing the cancer help-line, a service provided by the Cancer Council. These participants also took part in formal psychological or counselling services. In total, six participants reported accessing psychological or counselling services. Two participants had met with a psychologist, one had met with a social worker, one had received counselling at a hospital whilst receiving radiotherapy, and another received additional sessions for a pre-existing condition¹⁹. The sixth participant received counselling

¹⁹ Apparently this patient was offered additional consultations via funding applied for by her general practitioner at an Adelaide Hills practice.

via the Cancer Centre. No participants reported any involvement with available support groups.

(ii) Lack of Referral to formal support services and/or community services.

Overall, patients could not recall being referred for psychological intervention, or informed about available support services. It is important to note that no one in this sample was directly referred to a psychologist for assistance, despite the development of psychological disorder following the diagnosis of cancer. Only those participants with pre-existing psychological disorder had engaged the services of a psychologist.

(iii) Professionals do not have the ‘cancer experience’

A patient who reported receiving psychological services reported seeing two psychologists; she stopped seeing one as “... she didn’t have a cancer perspective” [Female: Non Hodgkin’s Lymphoma].

(iv) Distress not serious enough to warrant professional services

A participant described her cancer experience as traumatic, though this person had not sought psychological assistance because she still did not think her distress was serious enough to contact a psychologist:

I think - you’ve been through a trauma - you may not see it now but you might later. So I would have liked a piece of paper, that gave me some names. Psychologist – no I don’t need that I ‘m not that bad.

[Female: Breast]

(v) Lack of information regarding available services

A participant expressed dissatisfaction with information available concerning support services; for example, she heard about the services of the Leukaemia Foundation when they were no longer relevant. Suffering extreme financial hardship (e.g., Private health was no longer funding hospital bills and the family home had been sold) this patient and her husband had been paying for petrol and car parking to travel to the city everyday so that the patient could receive treatment. Only much later, when working as a volunteer at the Leukaemia Foundation, she realised that the organisation would have provided them with transport to and from the hospital at no charge.

(vi) Responsibility for providing information concerning available services

Participants were asked who they thought should provide them with information concerning support services. Responses varied and ranged from nurses to general practitioners, to oncologists, someone central in the hospital, or community service providers. Some patients believed this support should be provided by the main doctor responsible for their care: “Well, if they treat you to save your life, then the treatment should be ongoing, even if it’s psychological, it should be ongoing” [Male: Prostate]; and, “Probably the main doctor, or someone associated with him” [Female: Lymphoma]. There were exceptions, another patient stated:

Someone who is capable and confident in doing that, obviously my oncologist couldn’t well I guess he couldn’t because he deals with it everyday and each cancer patient has huge, individual emotion [sic] issues and he can’t deal with it because he just doesn’t have the time.

[Female: Stomach]

Another patient stated that: “A lot of pamphlets from cancer centre²⁰ – someone there everyday with those booklets that could direct people in the right direction” [Male: Lung].

²⁰ It was not clear from the transcripts whether the patient was referring to the Cancer Council or the Cancer Centre.

(vii) Brochures – not an adequate way of providing information.

Patients reported receiving too many brochures that they did not read them because they were not sure of their relevance. One patient said she was given brochures by a breast care nurse only then to be told by her surgeon to ignore them.

When I saw the surgeon he told me to throw them all away because [sic] out of date. She's telling me to read them, and he [sic] telling me to throw them out. I think a younger person wouldn't cope with that.

[Female: Breast]

6.7.6 Substantive Code 6: Possible Impediments to Uptake of Support Services

(i) Support groups: Lack of connectivity/relevance.

Negative comments concerning support groups included: "I'm not them, I'm going to beat it ...Don't really want to hear other peoples' problems as had own" [Male: Head and Neck]; "Feel like people be sitting around and say mine was worse than yours" [Female: Breast]; "Sometimes I think that sort of thing might bring you down" [Female: Lymphoma].

Another participant said there were impediments in terms of their location. "Wasn't lazy – put it this way, don't drive" [Male: Prostate].

(ii) Preference for support at the end of treatment

Despite these negative comments several participants noted that they would have been more willing to consider participation in support groups at the end, rather than at the beginning or during treatment. Although several participants thought support groups were a good idea, they did not see themselves as being involved.

(iii) Preference for one-on-one communication.

Several participants reported a preference for support on a one-on-one basis. The need for this kind of support was identified by some participants as being necessary at the beginning, middle and end of their illness experience. “When I was first diagnosed I would’ve loved to have someone, in the hospital that would have just sat down and talked to me” [Female: Acute Myeloid Leukaemia]. This participant also noted that she would have liked this communication when receiving treatment. “Try to take time to talk you but others pretty young, the system doesn’t allow for it. In an isolation bay, wasn’t that chance to mingle” [Female: Acute Myeloid Leukaemia]. Although during her experience, she said she had one isolated time where she received support from an oncology nurse. “I was down some days and spoke to oncology nurse. She was very supportive and talked to me and talked through things. That was the only time” [Female: Acute Myeloid Leukaemia].

6.7.7 Substantive Code 7: Factors linked with evaluations of health care

(i) Positive and negative frames of reference

The majority of communication encounters discussed involved oncologists and surgeons; however, communication experiences involving other health professionals were also recounted (e.g., general practitioners, radiology staff, registrars and nurses). When participants described their communication experiences with medical professionals, participants tended to recollect specific instances where they had either positive or negative communication experiences. They tended to describe these experiences in terms of being helpful/or not helpful and these descriptions appeared to be linked with their perceptions concerning the quality of health services received.

(ii) Negative experiences linked with health system

The negative experiences recounted mainly involved general practitioners or other allied health workers. Negative experiences seemed to be associated with a lack of training in specific departments (e.g., radiology), poor attitudes or communication skills. A female

breast cancer patient was shocked when a general practitioner commented: “So I suppose the surgeon said he got it all? Well they never do”[Female: Breast]. This patient also expressed dissatisfaction with other aspects of the consultation with the general practitioner. According to the participant, the general practitioner refused to take her on as an ongoing patient because she was middle aged and was likely to have too many chronic issues requiring attention.

A female patient with Non-Hodgkin’s lymphoma recounted her experience with radiology staff where it appears that staff may not be given adequate training in dealing with patients who are about to receive a life-threatening diagnosis.

From the very first day when I had my scan, that was probably one of the most horrible days, not only was I given the diagnosis, but the staff did not seem to know how to treat you. Just came across blank looks; if they had of been trained in explaining the process that would’ve been useful.

[Female: Non-Hodgkin’s lymphoma]

Negative experiences with health services were not always attributed directly to particular health professionals; instead, the health system was seen as imposing particular constraints (e.g., time, lack of resources). Participants reported a range of negative communication experiences; again these experiences appeared to impact on patients’ perceptions regarding the quality of health services received. The majority of these situations were not linked with interactions involving specialists.

For example, participants did not blame specialists for time-constraints and instead blamed the government and/or allocation of resources (e.g., “should be worrying about own backyard” [Male: Head and Neck diagnosis), or other constraints of the public system (i.e., understaffed, and overworked).

Nothing against the doctor and I think it's the system but like he told me: "You've got cancer have you got any questions. And I said 'no', like a stunned mullet. And then the next time, I wrote down questions, but unless you know what's going to happen you don't know what questions to ask.

[Female: Stomach]

(iii) Positive accounts of specialists – a focus on competencies

When describing communication experiences with specialists, generally positive accounts of experiences were recounted. Participants tended to describe personal characteristics of the specialist. Many emphasised the competence of the specialist. For example, "he was a brilliant surgeon" [Female: Recurrent Diagnosis, Stomach]; "he's obviously very good at what he does" [Female: Breast].

(iv) Helpful/not helpful behaviours

Helpful behaviours included characteristics such as sensitivity, kindness, empathy, being nice, encouragement and concern. Unhelpful behaviours of oncologists and surgeons included: bluntness, lack of compassion, lack of sensitivity, negativity, casualness. For example, a participant who had terminal cancer reported being deeply offended when the specialist was judged to be too casual when delivering a diagnosis.

He came in casually eating his lunch and said stage 3, but probably stage 4 and don't expect to live to an old age; you've probably only got about 8 years. So [I] didn't go back to him. Been doing this job too long; you've lost your sensitivity completely.

[Female: Lymphoma]

(v) Inadequacies overlooked, use of stereotypes and an emphasis on competencies

When specialists did not show such preferred characteristics, patients generally focused on their competence as a specialist and/or surgeon and in some instances excused their behaviour

as being characteristic of a specialist or surgeon: “you know what surgeons are like” [Male: Lung]. Or, again because of the health system or a lack of available time.

(vi) Rapport: depersonalisation, openness, similar interests, doctor-patient distance

Patients noted the importance of rapport particularly in terms of the ‘quality’ of subsequent consultations; however, there appeared to be several factors that led to perceptions of the existence or absence of rapport. Patients described the doctor patient distance as necessary but sometimes too de-personalising.

Participants regularly acknowledged that medical professionals, in particular oncologists and surgeons, had a difficult job. They also acknowledged the time constraints and pressures to see many patients, but still frequently reported feeling like a number. They expressed a need for empathetic communication but not sympathy. “A lot of times a number, not a human being” [Female: Breast].

The development of rapport over time was linked with a sense that the interaction was becoming more personal and allowed for an increased amount of openness to respond to questions. For instance, one patient noted that in the beginning, a specialist was reluctant to provide information but as rapport developed, more information was provided.

In the beginning he gave us the barest of details but as he got to know us, “[he] opened up would take the time to answer.

[Female: Acute Myeloid Leukemia]

Rapport was quicker to develop (at least as reported from the patient’s perspective) in male-male interactions whereby similar interests (e.g. sport, fishing) were noted.

Ah the specialist, is a good guy ... I've seen him every 3 months and he's great and we mostly talk about women and cars and wine and things like that so it's really good.

[Male: Head and Neck].

viii) Doctor-patient distance – feeling like a number

The sense that one was treated as a number, not a person, was not only applicable with respect to comments directed at specialists but extended to other health professionals. For example, one patient reported on contacting a breast care nurse following surgery.

I did call once but really didn't feel that there was much support there. This is how it is. Of course you are going to feel uncomfortable, of course this.... They have hundreds of people – they can't make everybody feel special. And you're just a number.

[Female: Breast]

(vii) Preference for information: individual differences

Individuals expressed different needs for information, with some preferring a minimal amount (i.e. 'less the better' [Female: Breast]), and in contrast others wanted more technical accounts. The failure to give information when specifically asked was linked with the expression of immense frustration and possibly feelings of anger not only from the patient but maybe also from the specialist. A patient commented on her oncologist's response when she asked for technical information.

He yelled at me. Far too technical and all you want to know is that you're cured. They want you sit there and listen and do what they tell you to do. It's your body. I still have the right to ask a question.

[Female: Breast]

(viii) Preference for particular interactional styles

Within this sample, significant variation in terms of the style of interaction preferred was evident. Some patients perceived that their oncologist was overly negative (i.e. citing the

percentage that the cancer will re-occur, rather than the percentage that the cancer will not reoccur). Others preferred to know the worst-case scenario so that plans could be made for the future. Other participants preferred a blunt approach: “he pulled no punches [Male: Lung]. Moreover, “he didn’t try to sugar coat it too much or anything [Male: Bowel). In contrast, others preferred a more sensitive, gentle approach. “There are ways of saying things, [sic] understand work with people that sometimes die but need to show a bit of compassion” [Female: Breast].

(ix) Lack of holistic approach

The focus on disease may also contribute to depersonalising the consultative experience. Participants noted a lack of interest in emotional aspects; a lack of interest in their general physical condition; or a “fobbing off” of physical complaints if not directly related to the diseased organ; and, a “fobbing off” of physical conditions reported if perceived not to be explicitly associated with treatment. One participant who had reported symptoms of osteoporosis to his specialist said that he was ‘fobbed off’ by the specialist. Some months later, he was diagnosed with osteoporosis. He said:

Doctors’ should listen. If something’s not right with one’s own body, then doctors should listen. We’re only a number.

[Male: Head and Neck patient]

Some participants suggested that the interest of the specialist was confined to the affected organ. A participant contrasted her experiences with a registrar with a surgeon. Central to this participants account was that the registrar also looked at other symptoms and recommended that she see other specialists for ongoing physical issues.

Lovely lady, had the time, treated me as a person ... She showed that she knew me and looked at me as the whole person, whereas he was the ovary, there I've done my job.

[Female: Stomach]

(xi) Focus on Disease

Another participant with a terminal condition, described her specialist as helpful but was disappointed that she was not treated, only the disease.

They're very helpful but its all to do with the disease not how your feeling but they treat the disease itself , they're not really interested in how your feeling physically, they sort of brush that off, that's not my field . See your GP and get them to refer you to someone ... They might be very caring in dealing with you in other ways but when it comes to anything other than just the cancer it's not their field... Very stressful because [sic] never know when its going to get you yet the doctors still just treat as a disease and not how it's affecting you emotionally.

[Female: Lymphoma].

(xii) Lack of multidisciplinary approach

Others described the lack of communication across doctors and different specialties

Others noted that files did not contain up to date information, and in one instance – and as reported by a participant - a file was lost; the participant reported that she was sent to radiotherapy and was meant to be receiving chemotherapy. Others with complicated side effects [menopause, osteoporosis, feeding issues, dental issues] were 'frustrated' by the lack of communication among various health care providers [Female: Head and Neck].

According to this participant, considerable time and energy was spent in recounting her medical history to various specialists and health providers.

6.7.8 Substantive Area 8: Patient Expectations

(i) Expectations differentiated according to health professional

Other questions embedded within the interview schedule sought to understand whether patients' expectations were met in terms of their experiences with their doctors. There is some repetition in terms of the codes identified but nonetheless the reporting of codes across several categories is consistent with the premises and recommendations of Glaser's (1992) account of grounded theory. A failure to do so may impede the development of theory.

When responding to the question concerning whether their expectations were met, patients tended to differentiate among health professionals and suggested that for some professionals their expectations were met whereas for others they were not. For example, "Local doctors no.... Surgeon, yes" [Female: Breast].

(ii) Emphasis on competencies of doctor in terms of treatment and survival

When patients were explicitly asked if their expectations were met, the majority of participants simply responded with a 'yes' and made comments with regard to their disease state, for example: "I'm still here, so he must've been pretty good" [Female: Breast].

Another patient said: "In many ways yes, in many ways no. The fortune of just being alive is more than the expectation I was given ... of course I didn't want to die" [Head and Neck: Male].

(iii) Expect application of the biomedical model

Furthermore, patients' expectations appeared to be shaped by their prior experiences with the biomedical model of disease.

At the first appointment I thought he would do some kind of examination and make some kind of value judgement on what he thought and then make a suggestion for some sort of treatment and that is basically exactly what happened.

[Male: Head and Neck]

(iii) Characteristics of specialists

Again, an emphasis on characteristics of certain health professionals was emphasised. In some instances, the notion that specialists confer with, or can be stereotyped into particular types of individuals was noted.

Ah, Doctors...yeah. They've got a job to do, and I think the one's you see at this level, well they are 'Specialists'. They're equivalent to 'Executives' in the public service, you know – they do what they have to do. I feel for them and their job is incredibly hard and they see so many people.

[Female: Breast]

(iv) Communication experiences

Similarly, communication experiences were prevalent in participants' responses. For example, a participant explained:

Very nice, very caring – quite understanding, and when [he] got the results after surgery [he] didn't wait for two days [he] rang me. Didn't have to do that but he did. And said that he loves good news as much as the patient does

[Breast: Female]

Again, particular styles of communication, and the information and/or openness surrounding their interactional style were commented upon:

Yes [i.e. expectations were met]. Didn't beat around the bush. You have lung cancer ... hit right between your eyes. Then he followed up, but it's operable. Then explained the steps.

[Male: Lung]

A patient who said that her expectations were not met said:

No. What were things [sic] that didn't do well? Answer my questions and a lack of communicating with each other concerning a patient's treatment.

[Female: Breast]

(v) Continuance of care.

Another patient noted that he expected that the care with his specialists would continue indefinitely.

I can't complain as I haven't had to put my hand in my pocket, so I'm very grateful. But don't think it should stop. If you're still alive then the treatment should continue, unless they can guarantee ...

[Male: Prostate]

(vi) Acknowledge role of alternative therapy

Another participant noted that whilst she was happy with aspects of the treatment, she was immensely disappointed when her specialist 'dismissed' her account of how alternative therapy had helped her. She was receiving massage for potential lymph node swelling, and whilst she did not have a specific problem with swelling, she was participating in massage as a 'preventative strategy'.

... On the whole, really happy with it, but one problem - when went back. I keep hitting myself over the head, and thinking God [participant name] what were you expecting. I think so, but I think why was I expecting anything [Participant starts to cry]. I think it was because he was not giving enough recognition to the alternative therapy and just dismissing it. And to me, that's what helped me get through, when the medicine people weren't there, it was that, that was what helped.

[Female: Breast]

Another participant who prior to receiving a diagnosis of cancer was a practicing alternative therapist and teacher at an alternative therapy college reported how her colleagues ostracized her for taking the traditional medical approach to curing her cancer (i.e. surgery and chemotherapy). Whilst she was happy with the treatment of her cancer she said that her expectations were not met.

No, my expectation is that if I spoke to a doctor about an alternative method that they would sort of talk to me like a human being. And that I knew something. But I was dismissed. My own GP, although I've got the same GP because she's thorough but if I say to her what do you think of ... [She says:] I wouldn't know about that - I'm a medical doctor. She will not discuss any other method - in a way she basically talks down to me. The only doctor that didn't was ... he didn't talk much though but he had a genuine warmth about him. And he would listen to you ... [Others] don't listen, not interested ...

[Female: Breast]

(vii) Expectations to be treated versus emotional aspects

It appears that patients have at least two types of expectations concerning their doctors. The first concerns what the doctor does for the patient in terms of their disease. The second includes an expectation that they will be provided with some form of emotional support. For example, when responding to the question: In terms of your experiences with your doctors, were your expectations met? A participant responded:

GP, oncologist and surgeon, yes only my surgeon. I think what my oncologist did yes, but emotionally no.

[Female: Breast]

(viii) Expectations multi-dimensional

Responses indicated that patients' expectations contain several components. In the following comment, the patient emphasises 'treatment' and 'rapport'.

That's a hard one. [Delay] I guess so. I expected to be treated and I was. Doctor's became more approachable.

[Female: Acute Myeloid Leukemia]

6.7.9 Recommendations

Participants were explicitly asked to propose recommendations. For example, they were asked, "In terms of developing recommendations for other people living with cancer, do you think or feel that anything could have been done differently? The major recommendations offered in response to this specific question included: More money into health system; one-on-one support as opposed to group support; not just focusing on the physical but also the emotional, acknowledgement of alternative therapies; informed of available services; more interaction; more integrated service delivery.

6.7.10 Involvement in intervention focused on the expression of emotion

Patients were asked if they were willing to participate in an intervention that used writing to express their emotions. Some participants were not sure and would assess according to their work and personal commitments and two participants would assess later depending on the treatment they were currently receiving. Others said they would be willing but did not acknowledge that there would be any personal benefit to them; instead, they said they would do it if it helped others.

Generally, there was a perception that others, perhaps who were younger or who had fewer resources, were not as strong as them. Even patients who had openly cried during the interview (perhaps indicating emotional distress) maintained that their participation would be to help others. Four exceptions were noted; 2 of these involved patients with head and neck cancer (1 male and 1 female); another involved a patient with a diagnosis of recurrence, and another female in remission from Non-Hodgkin's lymphoma. One female participant, in particular saw the benefits in writing as she found communicating verbally extremely difficult (i.e. others found it difficult to understand her communication). This participant had also

been communicating in this manner (i.e. expressing emotion) via email with relatives overseas. The other two female participants also reported having used journaling previously and had found it useful.

One patient did not think she would be able to participate and reported that:

Started to write a diary but gave it up as became too hard, felt as if I was reliving everything and found it was ineffective, whereas you feel you should be 'hopeful'. At the moment I couldn't do it. I couldn't concentrate. Difficulties with vision. By the time got into ...[sic], run out of money, no private health. Couldn't afford glasses. Don't do things we're doing (reading) [sic] gets too hard.²¹

[Female: Acute Myeloid Leukemia]

6.8 Application of PAR to Research Findings

In accord with the principles of Participatory Action Research (PAR; Elden & Chisholm, 1994; Kemmis & McTaggart, 2005; Susman & Evered, 1978) participants were encouraged to be active in the research process. This was achieved in two ways. Firstly, participants were presented with preliminary results of this research and were asked to assess the extent to which the findings were applicable and relevant to their experiences. During this process, they were encouraged to be critical of the results and were asked to identify instances in which the data did not apply to their experiences. Participants provided data that elaborated or confirmed some results, and proposed contradictions with respect to other research findings. Secondly, based on the research findings participants were presented with a range of preliminary options for intervention and they were encouraged to be active in refining and developing these recommendations. Participants were also provided with an overview of the

²¹ After participating in this interview the patient later experienced diagnosis of recurrence and participated in the intervention. Despite her ill health and encouragement to withdraw, she continued in the intervention until she died after completing 3 weeks of the scheduled 4 week intervention. She reported that the intervention helped her deal with things logically.

contents of the proposed individual level intervention and were asked to consider the extent to which the proposed intervention and its components were acceptable and relevant.

6.8.1 Focus group – Opportunity for Feedback

A power point presentation was prepared in order to summarise the emergence of codes relevant to cancer patients' experiences. This was presented to participants either at a group session or in individual sessions, held by the researcher. Participants who did not attend the group or individual sessions were also offered the opportunity to participate. A hard copy of the power-point presentation was mailed to participants and they were provided with a feedback sheet to complete and return to the researcher. These various options for providing feedback were offered to participants on the basis of findings emerging in this study that suggested that most participants appeared to show a preference for one-on- one communication. Feedback was received only from those participants who attended the group or individual sessions. All of these participants later went on to participate in the intervention, perhaps suggesting that they differed in some respect from those that did not participate.

6.8.2 Elaboration and Confirmation of Themes and Recommendations

Participants generally agreed that results and explanations provided were applicable and relevant to their experiences. As one participant commented: "Yes, it is a great overview of the situation as I experienced and feel". However, they added further information with respect to some codes (elaboration) and provided examples and instances where the results were not entirely applicable (contradictions), or provided further information that confirmed the categories as reviewed (confirmation). These results are reviewed as follows.

(i) Alternative therapy and communication with medical professionals

Participants reported that not all medical professionals were critical of alternative therapies. They felt that younger members of staff were more accepting of them wanting to do

'alternative therapy' and rather than be critical would simply acknowledge "whatever works for you". Some participants emphasised that they did receive emotional support from their specialist. Patients proposed that older specialists were more adept at handling emotional aspects than younger specialists, but reported that there appeared to be differences across specialties in terms of the extent to which doctors would listen. Participants attributed these differences to "different schools of thought" and/or "different training" and "different personalities". Patients also reported that they did not always directly seek emotional support from their specialists, and there appeared to be differences within the group in terms of whether or not they sought this type of support from their specialist.

(ii) Communication with friends and family

Members of the focus group suggested that during their cancer experience they were sometimes honest, but only with particular individuals and even then the general view was that people can only deal with this 'honesty' in small doses. One participant reported that some family members dealt with her cancer by pretending that it did not exist (e.g., "they thought if they didn't think about or talk about it, it might go away"). Others noted how helpless their immediate partners were during the process and commented that they often thought: "Where's the support for me?" One participant reported that her husband saw a grief counsellor at his work and found this helpful. A participant noted how much his partner wanted to help but did not know what to do. One participant, in recognising the distress that her partner experienced, said that she goes out of her way now to ask the partner of those with cancer how they are coping.

(iii) Dislike of cancer label

A participant noted how she did not tell anyone about her cancer because she did not want to be dealt with differently. Others agreed and suggested that others treat you as 'cancer' rather

than a human with cancer. One participant reported her reluctance to have treatment that would cause the loss of hair because then people would know she had cancer.

(iv) Positive spirit

The findings with respect to ‘fighting spirit’ and maintaining positivity appeared to resonate with research participants. They added the following comments: “Seen as a failure if not strong all the time”; “Have to be smiley all the time”; “If are having [sic] a bad day, people surprised that grumpy”. “Got to be strong as society expects”; “Family expects this”; “Pushed as preferred recovery method. Society expects to be strong and cheerful’

(v) Support services – elaborations

Significant improvements in the uptake of community services had occurred since the original interviews were conducted. Of the 10 participants, two had joined a breast cancer support group (e.g., Dragon Boat) another had become a volunteer at the Cancer Council (Cancer-Connect program), and another patient (head and neck cancer patient) established her own support group with assistance from the Cancer Council. Two patients had also accessed other community services (Cancer Care) for the first time. Participants reported being pleased with their involvement. One of these perceived that the group were ‘cliquey’ but would persist as she was interested in being active. The other participant noted how she liked the idea of participating in a water sport.

Another participant reported responding to a brochure concerning research that encouraged women to be active but she said that she was no longer involved and preferred to work with a personnel trainer. She reported that she was working towards a goal of being fit enough to go on an overseas trek. Another participant reported a preference for support groups or events such as weekend retreats where one could have the option of trying a variety of things.

Others reported engaging in leisure activities and alternative therapies (massage, meditation) and reported finding these experiences healing or nurturing.

(vi) Factors associated with participation/non-participation

Given that the majority of participants had not sought involvement in community services previously, patients were asked to offer reasons for their current participation. These included: onset of tears at unpredictable times (i.e. a realisation that not coping as well as thought); social reasons; and to be with similar others. When patients were asked why psychological or counselling support was not sought to deal with emotional issues, they described a reluctance to meet with professionals who had not been through the cancer experience. Reasons for non-participation either earlier in process, or currently included no need for services as they thought they were ‘coping well’ and were receiving support from family and friends; a lack of information/knowledge about available services; a perception that services provided are mostly for females with breast cancer. A lack of services, or knowledge about available services, specifically for men with a variety of diagnoses was noted.

(vii) Other support received

Two research participants noted that support (both physical and emotional) was received from district nurses.

(viii) Treatment – contradiction

One participant reported that she did not automatically take the doctors advice concerning the best approach to her treatment and sought a second opinion. She reported that taking this approach resulted in her feeling ‘alienated’ from her practitioner and she reported that ‘he didn’t like it’.

(viii) Continuity of care

When discussing ongoing symptoms, research participants noted the importance of follow up communication and continuity in care. Patients comments included: ‘This communication needs to be accessible’; ‘one- on-one care after’; ‘similar experiences’; ‘laymen terms’; ‘continuity of care’; ‘sense that nothing too trivial’.

(ix) Recommendations

Within the presentation, preliminary recommendations were presented to participants. These focused on a) educating health professionals regarding the importance of considering emotional aspects of the illness experience b) encouraging referral to psychologists/support services c) improving the manner in which information concerning support services is provided and d) improving the last appointment by potentially introducing a patient centered health plan. Participants were most interested in two aspects of these recommendations: improving the last appointment and improving the provision of information concerning support services. Research participants supported the following two recommendations.

- a) Establishment of support personnel from established organisations (e.g., Cancer Council) in the hospital environment to inform patients directly of relevant services available.
- b) A patient centered health plan to facilitate continuity in care. The plan would provide a history of diagnosis, treatments, chronic ailments and approaches to treatment. It would also incorporate patient goals. The end of treatment was recommended as an appropriate time to develop this plan.

It is important to note, that the researcher had initially proposed that the oncologist, or someone central in the hospital environment as the person who would provide information concerning support services. However, participants proposed that someone from a support

service organisation should provide this information. The critical factor here appeared to involve a preference for in-person communication that would increase the personal relevance of the services available.

6.8.3 Conclusion

Examples of the codes derived in open coding were provided and these were organised within 8 core substantive codes. As a result of involving participants in the research process, confirmation, elaboration and contradiction of these codes occurred. The adoption of the PAR approach, and the incorporation of the grounded theory approach to coding data reduced the potential for researcher bias in reporting. For example, contradictory data were reported in the focus group and thus this new data was incorporated by the researcher.

The formal literature was assessed to seek an explanation for the contradictory data. This process is described in the next chapter when results from the second stage of the analysis (i.e, theoretical coding) are presented.

7. DEVELOPING SUBSTANTIVE THEORY: INCORPORATING EXISTING LITERATURE

7.1. Overview

Many open codes were identified in Chapter 6, and these were selectively grouped into 8 main core codes. In this chapter, the analysis results in these codes being suffused into 3 higher order substantive codes (i.e. theoretical codes). These include: a) coping through communication: inhibition and positive spirit b) evaluations of care c) coping and support services.

Described in this chapter are the relationships among subordinate codes and their proposed relationship with theoretical codes. Specifically, explanatory models are presented; the purpose of these models is to show the relationships among codes and to propose hypotheses that could form the basis of future research. New data provided by participants during the focus group and individual sessions held by the researcher led to development of additional codes. These codes guided the literature search in seeking applicable and relevant theory. Criteria used in assessing theories focused on: i) the extent to which formal theory could provide a complete explanation of the results of this research and ii) the potential utility of the theory in developing further research and iii) the ability to inform individual and community level interventions.

Literature relevant to patient-practitioner communication was also sought and assessed for relevance and applicability when explaining the data. As will be reviewed, some of the hypotheses proposed on the basis of the data in this study are contrary to proposals made in the formal literature. In some instances, the findings suggest possible impediments to the implementation of public policy recommendations. Other formal theory, such as Hobfoll's (2001; 1989; 1988) Conservation of Resources (COR) theory provides a complete account of the data relevant to understanding the cancer coping process.

7.2 Coping through Communication - Inhibition and Positive Spirit

7.2.1 Data challenges traditional views of positive spirit and emotional inhibition

The formal literature with respect to coping strategies such as inhibition and fighting spirit has already been reviewed in this thesis (see chapters 4 and 5). As reviewed, concepts such as ‘fighting spirit’ and ‘emotional inhibition’ have received considerable attention in the cancer literature. The data in this study challenge previous research focused on these constructs. For example, the level of inquiry was shifted from an individual one and incorporated the social system from within which cancer patients experience their illness. The data indicated that the presence of particular coping styles (i.e. positive spirit), and inhibitory strategies appear to be more to do with responding to the needs of others, rather than a true reflection of the manner in which a patient initially adjusts to and/or attempts to cope with their diagnosis.

Furthermore, these constructs appear to be socially determined and not personally determined as is generally advocated in the literature. This finding appears to contradict Garssen’s (2007) hypothesis that constructs such as inhibition are personally related whereas constructs such as repression are socially related (see Chapter 5).

For instance, the concept of ‘fighting spirit’, and the development of an inhibitory coping style appears to emerge as a consequence of others’ reactions to cancer. As shown in Figure 6, in this study it was evident that patients’ responses indicated that they initially attempted to cope through talking but these efforts (unless with similar others) were unsuccessful due to the resistance of others in patients’ social network to engage in such communication. This failure to gain the kind of support that patients had expected was linked, in some instances, with interpersonal tension and a sense of distance in personal relationships. As a result, and to avoid upsetting others, patients changed their coping strategy and adopted an inhibitory approach to communication that was characterised by the ‘putting on of a brave face’.

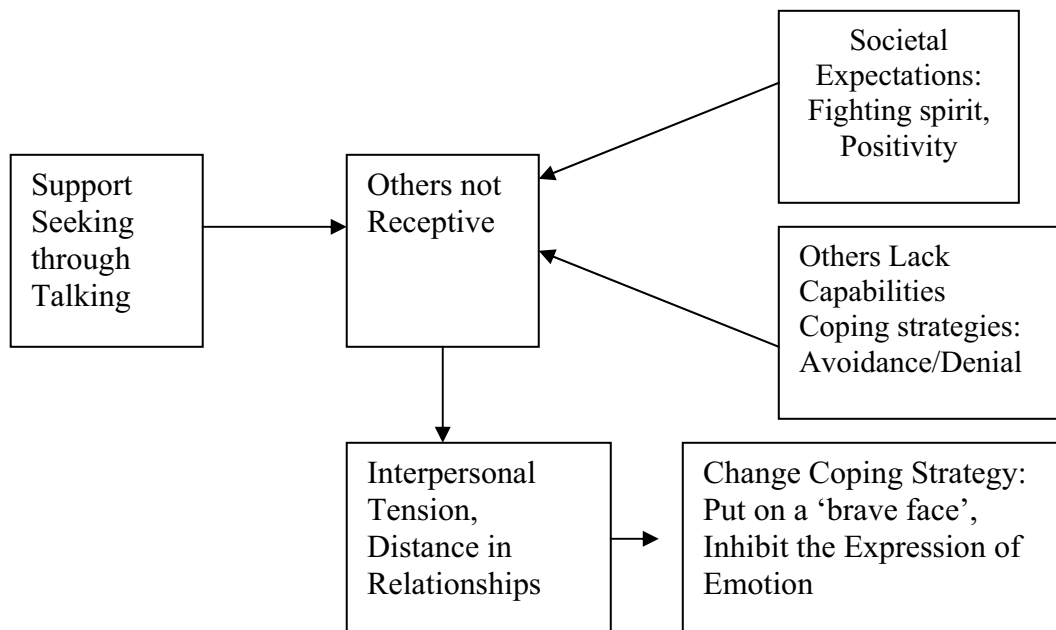


FIGURE 6.
Positivity and Inhibition: Socially not Personally Determined

Furthermore, as shown in Figure 6, societal attitudes concerning the role of ‘fighting spirit’ in curing cancer may influence the manner in which others in a patients’ social network react to their communication efforts. In addition, patients noted that others in their social network did not have the personal capabilities to know how to communicate about cancer and sometimes adopted a coping strategy involving denial or avoidance. For example, as reviewed in Chapter 6, others avoided talking about cancer or communicated about superficial matters (sport, weather).

7.2.2 Review of hypotheses generated and recommendations for intervention

Future research may assess the extent to which constructs of inhibition and fighting spirit are personally, or socially determined. The dominant view within the cancer coping literature is one that suggests that tendencies to inhibit emotion are personally determined and impact on the way an individual reacts to and adjusts to a diagnosis of cancer. The results of this research challenge this view. Further research would assess the validity of this claim by focusing on others in patients' social networks and assessing the extent to which they endorse concepts such as fighting spirit. In addition, research could examine how others in patients' social networks react when the patient 'fails' to demonstrate a 'fighting spirit'.

Interventions could focus on providing cancer patients and their families with education concerning the coping process. In particular, emphasising the different expectations and attitudes patients and families may have concerning positive spirit, and the expression of emotion. Community level interventions could focus on educating the public concerning misconceptions they may have concerning the role of positive spirit in curing cancer. Other community interventions that continue to facilitate communication with similar others will allow patients to express how they are really feeling. It may be appropriate to provide treatment in shared facilities whereby patients have the opportunity to engage with others in similar circumstances.

7.3 Evaluations of Care

(1) Practitioner behaviours or doctors' competencies?

To assess the extent to which formal psychological literature could provide an account of the data in this study, a review of literature focused on improving patient-practitioner communication was performed. Generally, the formal psychological literature focuses on improving communication between doctor and patient; the unit of analysis tends to focus on practitioner behaviours. In the formal literature the presence, or absence of particular

behaviours (e.g, empathy, encouragement, information giving, encouraging participation in decision making, doctor passivity and listening) are linked with outcomes such as patient satisfaction and other outcomes such as compliance and comprehension of medical information (Beck, Daughtridge and Solan, 2001). Moreover, the literature suggests that complaints concerning doctors have little to do with their competencies, and instead concern issues of communication (Meryn, 1990).

In this study, patients noted preferred practitioner characteristics (e.g., empathy) when describing helpful and unhelpful behaviours. However, in many instances, specialists were excused if their communication skills were less than perfect and indeed patients did not always expect that specialists would have endearing characteristics. For example, patients had formed particular stereotypes concerning how they expected specialists to interact. Furthermore, doctors' competencies were linked with patients' expectations concerning 'survival' and appeared to be linked with perceptions that they were receiving the best treatment possible. Thus in this study, evaluations of the quality of care received by specialists appeared to be based on their competencies, not their communication skills.

A possible explanation for these discrepant findings is that perhaps in interactions dealing with a life-threatening condition such as cancer, practitioner characteristics are not judged to be as important as other characteristics (e.g. competencies of specialists). This conclusion is consistent with findings reported in a previous study that showed that an intervention focused on improving doctor-patient communication in a cancer sample was not associated with improved patient satisfaction (Shillings, Jenkins & Fallowfield, 2003).

(ii) Rapport most important communication factor

Furthermore, preferred attributes of the specialist appeared less important than the existence of rapport in which the patients' views were valued and in which the communication was

respectful and non-dismissive of concerns. Factors potentially associated with the development, or break down in rapport are shown in Figure 7. Doctor-patient distance is shown as a mediator variable with downward arrows identifying factors potentially associated with increasing doctor-patient distance. For example, participants were particularly sensitive to communication that depersonalised the consultation, or forms of communication that dismissed their concerns, on an emotional or physical level. In contrast, upward arrows identify variables potentially linked with decreased doctor-patient distance. For instance, patients described individual preferences for information and the interactional style of the practitioner (sensitive versus blunt). This finding is consistent with a previous study that showed that cancer patients have individual preferences for communication and that the quality of the interactions with medical professionals is highly valued by patients (Butow, Kazemi, Beeney, Griffith, Dunn & Tattersall, 1996). Although in this previous study, the results indicated that patients had expectations concerning the quality of interactions concerning participation in decision making concerning treatment (Butow et al., 1996).

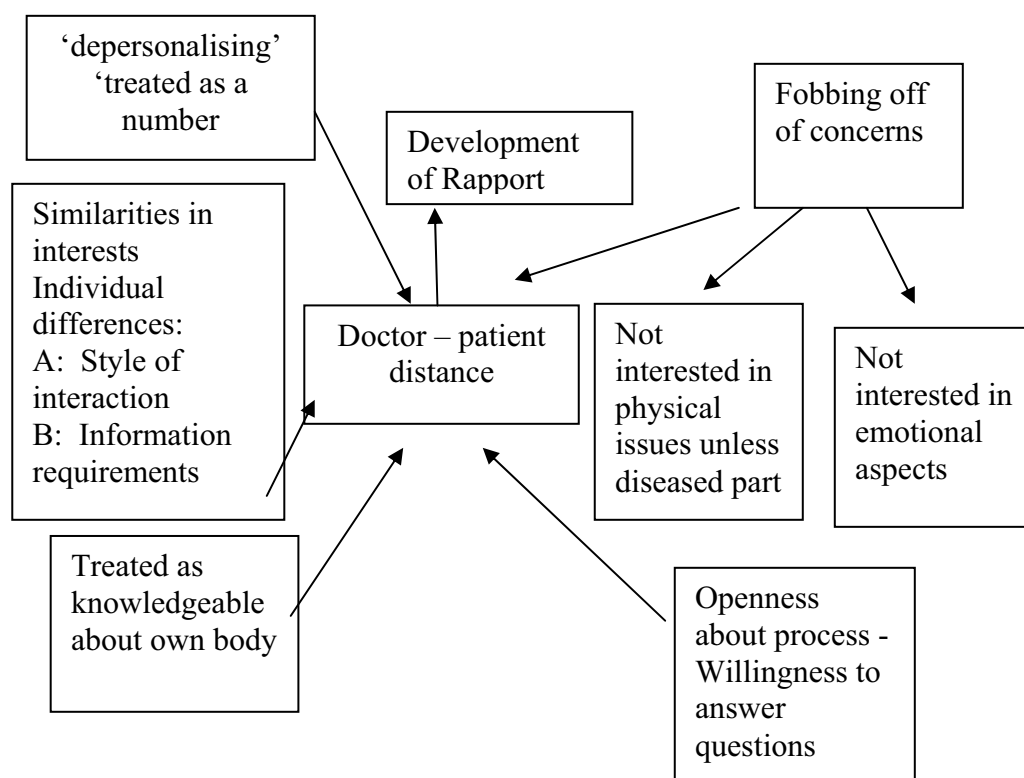


FIGURE 7
Factors Impacting on the Development of Rapport

(iii) Shared decision making – lack of acceptance, lack of competencies?

According to Beck et al. (2001) doctor passivity as opposed to doctor directedness in communication is particularly important in predicting health outcomes, including patient satisfaction. The results in this study contradict this hypothesis. For example, when patients were faced with a life-threatening condition, participants generally believed that specialists were in the best position to decide on the appropriate treatment and patients were not dissatisfied with such an approach. Whilst a lack of participation in decision making does not appear to impact on perceptions of the quality of treatment received, the passivity of the patients during their illness experience may have implications for their overall adjustment to cancer. Throughout the illness experience patients appear to relinquish their control to the doctors (i.e., believing that they do not have the capabilities to be involved in treatment decisions). When patients exit formal services, they appear to experience considerable distress. Due to being passive during the entire treatment process, patients may be at risk of experiencing a sense of helplessness as the primary care giver (i.e. the specialist) is no longer present in their lives.

In Chapter 1, when reviewing Australian initiatives that aim to encourage Shared Decision Making (SDM), it was noted that a lack of research has been performed in Australia. Nevertheless, in studies conducted abroad, generally organisational level, and practitioner factors are cited as impediments. Based on the results reported in this study, it may suggest that further research is required to assess patient level factors such as acceptability of SDM initiatives. The major patient level impediment identified was that patients perceived that they did not have the knowledge or expertise to be involved in decisions concerning appropriate treatment options. Future research could explore the role of patient level factors such as patient acceptability and/or patient competencies as potential impediments to implementing SDM models. Furthermore, the role of patient passivity in predicting

adjustment post the acute stage of the treatment experience is warranted. For instance, Butow et al. (1996) suggest that participation in treatment decisions is linked with improved psychological adjustment.

(iv) Patient expectations

Formal literature on patient expectations was also assessed. Previous research investigating patient expectations has focused predominantly on physical and/or medical intervention needs (e.g., requests for prescriptions) (Kravitz, Callahan, Karhman, Antonius & Lewis, 1997; Peck, Ubel, Roter, Dorr Gould, Asch, et al., 2004), not aspects of communication or psychosocial needs. Although, as noted previously, a study by Butow et al. (1996) did incorporate an understanding of patient expectations concerning their communication with respect to treatment issues.

In this study, the results indicated patients do have particular expectations concerning how they would like health professionals to interact, however, in the case of the specialists, unfulfilled expectations do not appear to impact on evaluations of care with respect to the specialist.

(v) Factors implicated in patient evaluations of quality and satisfaction

Shown in Figure 7 is a model that attempts to identify factors implicated when patients make evaluations concerning the quality of the care they receive. As noted, the existence of rapport and the presence of open and respectful communication does appear to be an expectation that patients have and may be important in terms of understanding evaluations of patient satisfaction with their specialist.

As shown on the left hand side of Figure 7, patients' expectations of doctors, particularly early on in the illness process are focused on the competencies of doctors and evaluations of

the quality of care they receive are based on disease outcomes (i.e. survival). At this stage of the illness experience the patient is expecting the application of the biomedical model of disease.

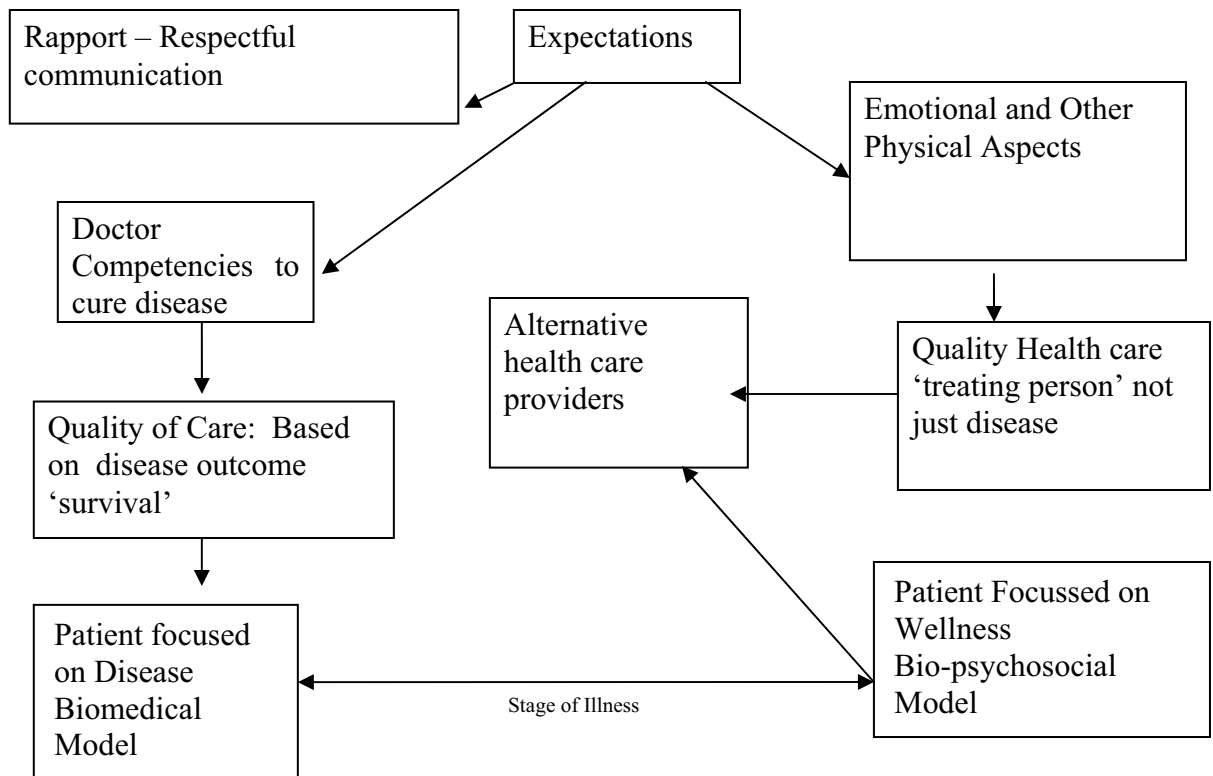


FIGURE 8
Expectations and Evaluations of Care

Other preferred characteristics of practitioners are not shown in the model. For instance, whilst patients do have expectations that doctors will display certain characteristics, they were not surprised when these qualities did not exist. In some respects, the existence of these qualities, along with the provision of emotional support, appear to be viewed at secondary levels to that of having the disease treated. As noted in Chapter 6, if there were inadequacies in terms of providing emotional support, specialists were not necessarily blamed for this. Instead, patients attributed such failings to the health system (e.g., lack of time, resources).

Thus, a failure to receive care based on a holistic model of care (based on physical and emotional needs) does not appear to directly impact on perceptions of satisfaction with specialists as patients attribute failures to impediments at the health system level (resources, lack of time). In contrast, perceptions concerning whether all expectations were met (i.e. received care based on a holistic model of care) do appear to impact on perceptions of overall care provided by the health care system. This proposal is shown in Figure 8 along the right hand side of the figure.

Ultimately, receiving quality health care services appears to be linked with the provision of emotional support, a holistic approach towards illness, incorporating other physical conditions. As shown in Figure 8, it is possible that a specialist can meet all patients' expectations; however, it also depicts patient expectations as they relate to the health care system level. Furthermore, the seeking of alternative therapies may be linked with patients' perceptions that their needs (i.e. on physical and emotional dimensions) are not met within the traditional health service delivery model.

For instance, as part of the ongoing coping process, patients particularly after completing formal treatment, appear to feel the need to get well. At this stage of the illness process, health is not conceived of in terms of 'the absence of disease' but is defined in broader terms, incorporating the emotional and sometimes spiritual. At the end of the treatment process, patients are focused on a more holistic approach to health that is consistent with the bio-psychosocial model of health. At this point, patients reported that the current health system did not meet their needs and several sought involvement in alternative therapies.

Evidence for shared care

As reviewed in Chapter 1, several initiatives focus on encouraging the adoption of innovative models of care with practitioners treating chronic illnesses in a holistic manner (i.e. incorporating psychological factors). In addition, with respect to the major chronic illnesses

that impact on disease burden, specific recommendations have focused on providing personal health records, improving communication between general practitioners and specialists and establishing and facilitating linkages with multidisciplinary services (NSW Health, 2001). In this study, patients did not perceive that their illness was managed in a holistic manner with patients reporting a focus on the disease and a lack of a multi-disciplinary (i.e. shared care) approach. It is important to note, however, that the application of a shared care model appears to be most applicable to patients after treatment, because earlier in the process patients are also focused on the disease.

Summary and recommendations

Generally, previous research investigating patient perceptions of the quality of care (i.e. communication, expectations, satisfaction) has focused on one specific consultation. Thus, such an approach is unlikely to capture, and subsequently distinguish between evaluations patients may make at the practitioner level versus those they make at the health system level. Participants' perceptions concerning whether they received high quality of care appear to extend beyond issues of doctor-patient communication, and potentially encompasses their experiences and use of the health care system. In the existing literature, research participants generally are not given the opportunity to describe their satisfaction in terms of the health care system, or with respect to the range of health professionals involved in their care. Instead, the interactions studied involve primary care interactions involving one doctor and one patient.

An appropriate response towards patients' use of alternative therapies should be implemented. Although doctors may be skeptical concerning the benefits of alternative therapy, if they are used to improve patients sense of wellness (not to cure cancer) then doctors should not be dismissive. Doctors are encouraged when dealing with different cultures to be sensitive to their attitudes and beliefs concerning illness. Thus, an appropriate response should also incorporate patients' attitudes and views concerning alternative therapies.

Within the current health system model where demands are high and resources are limited and the predominant focus of specialists is on treating cancer, specific recommendations for intervention could focus on a) providing patient education concerning the role of their specialists in providing care; b) adding support for specialists and surgeons so that adequate referral mechanisms exist and are promoted to patients in terms of dealing with emotional aspects of their illness; c) educating patients regarding the role of their general practitioner in terms of assisting with their overall health care; and, d) provision of multi-disciplinary teams to ensure that patients receive treatment and care in both emotional and physical domains. Future research could investigate whether such an approach may reduce the use of alternative therapies.

7.4 Coping and Support Services

7.4.1 Previous research: Support Services underutilised

In attempting to reduce the impact of cancer, many community organisations throughout the world offer a range of services for cancer patients and their families (for reviews see: Crawford, Rutter, Manley, Weaver, Kamaldeep, Fulop & Tyler, 2002; Tesauro, Rowland & Lustig, 2002). Despite the availability of services they appear to be grossly underutilised. For example, throughout Australia, 595 support groups exist, although just 5% (The Cancer Council, 2005) to 6.5% of those diagnosed with cancer participate (Pascoe et al., 2000). In addition, a recent evaluation of the Australian Cancer Council's helpline Jefford et al. (2005) reported that of 76,000 calls made to the helpline, the majority were from patients without cancer. Admittedly, the service is also an information service thus it is likely to receive calls from those seeking general information concerning cancer.

Previous research suggests that patients who engage in either formal psychological treatment and/or community support services are younger than the average cancer patient; have higher

levels of education; more knowledge about available services; favourable attitudes towards psychosocial support; report a poorer mental state; express a desire for help; and a need to cope with their illness (Pascoe et al., 2000). Barriers to participation reported include a lack of awareness of services available and a failure of health professionals to refer (The Cancer Council, 2006). Few studies focus on understanding why patients do not seek support; however, in an Australian sample patients reported a lack of need perceiving that adequate support was received from family, friends and doctors (Pascoe et al., 2000). Other studies suggest that patients have unmet needs with respect to information (Fallowfield, Ford & Lewis, 1995) communication (McWilliam, Brown & Steward, 2000) and emotional support (Butow et al. 1996).

Data from the research interview indicated a limited uptake of established support services and formal psychological services. Given that fifty percent of the sample was assessed to have a psychological disorder, a lack of need does not provide a complete explanation for the low levels of uptake of services observed in this study. Although in feedback provided by patients, they did identify factors associated with a lack of need: receiving adequate support from family, friends and religious or spiritual involvement. Other factors linked with the lack of uptake of services included: a lack of information and a lack of formal referral to psychological or community services.

7.5 Assessment of the Literature: A Focus on Pro-activity

As noted, during the interviews, participants had expressed somewhat negative comments about support groups. Furthermore, patients did not appear to have been informed about the availability of community services. Yet, some months later, when providing feedback, several participants had become pro-active in their efforts to be involved in support groups and community services.

7.5.1 Criteria Used to Assess the Formal Literature

The researcher assessed the formal literature for theory that might explain this change in participants' willingness to participate in support groups and community services. A particular focus when assessing the literature was to locate a theory that might include a concept such as pro-activity, particularly as applied to seeking support and/or becoming involved in new activities. Other important criteria in terms of evaluating the relevance of theory included the utility of theory to inform future research agendas and interventions. An important criterion in grounded theory is that the theory provides a complete account of the data (Fernandez, 2004). Thus, whilst providing information concerning 'pro-activity', the theory must also accommodate other results emerging from this study, and potentially other studies reviewed in this thesis.

7.5.2 Psychological Hardiness/Resilience

In reviewing available literature, it was apparent that several stress theories could provide an account of some aspects of this study. For instance, Kobasa's (1979) concept of 'hardiness' and Werner and Smith's (1989) concept of 'resilience' certainly applied to patients who reported that their cancer treatment had little impact on them. For instance, some patients in this study continued to work and engage in usual activities; these patients also tended to report few adverse side effects and generally no long term or ongoing chronic illnesses were reported. Hardy individuals are those who view change as a challenge as opposed to a threat, have a strong sense of purpose and commitment, and have high levels of personal control over events that occur in their lives. Similarly, Werner and Smith (1989) describe resilient individuals as those who have high levels of control, and face and endure stressful situations with little or no negative effects.

Not all participants in this study would be described as hardy and/or resilient. Approximately 50% of participants had a psychological disorder, although admittedly not all disorders occurred as a result of cancer. Similarly, the concept of control emphasised in both hardiness

and resilience concepts may not be applicable to patients when dealing with a stressor such as cancer. When dealing with a life-threatening illness such as cancer, issues of control, particularly for those individuals with high levels of internal control may prove problematic and lead to increases in perceptions of distress not decreases. For instance, previous research involving Rotter's (1954) locus of control theory suggests that individuals with an external locus of control (i.e. attribute causes of events to external forces such as luck or fate) cope better with cancer than individuals with an internal locus of control (i.e. attribute the causes of events to internal and dispositional causes). For example, Burish, Carey, Wallston, Stein, Jamison and Lyles (1994) report that in their study involving 62 cancer patients, an external locus of control, rather than an internal locus of control, was associated with lower levels of negative affect and physiological arousal. They cite the work of Wortman and Dunkel-Schetter (1979) to explain these findings and suggest that: "internally oriented individuals with chronic disease become frustrated and helpless because of their inability to change their health status appreciably" (Burish et al. 1994, p. 326-327).

In this study, patients who were attempting to regain control over their health and wellness by using alternative therapies did report frustration when dealing with medical professionals. In such instances, these individuals were particularly upset and emotional. The intensity of emotional outbursts present among participants when recounting these experiences may have involved additional issues or processes other than those involving communication. Issues of control could certainly provide an explanation for these findings and may be particularly applicable for those individuals who usually have high levels of control in other domains of their lives. A lack of control, for example, is linked with helplessness and depression (Seligman, 1975). Generally, however, patients in this sample did not endorse a helpless-hopeless coping style (see Chapters 4 and 5).

7.5.3 Emotion Focused and Problem Focused Coping Strategies

Lazarus and Folkman's (1984) theory of coping has some relevance to the data obtained in this study. According to this theory, in response to a stressor individuals engage in two forms of coping: emotion-focused coping and problem-focused coping. Although Lazarus and Folkman (1984) did not propose that one approach would be superior to the other, generally empirical evidence supports the hypothesis that problem-focused approaches to coping are more adaptive and lead to reductions in distress. However, as noted by Stanton et al. (2002) this finding may be due to the confounding of distress as the items included in measures that assess for emotion-focused coping also assess distress (see Chapter 4). Problem focused coping predominantly refers to efforts at dealing with the stressor and typically involves attempts to change the stressor itself. In contrast, emotion focused coping refers to efforts to manage the emotional distress that is associated with the stressor. An emotion-focused strategy can also include the use of denial, or emotional defensiveness.

Billings and Moos (1981) review a range of emotion focused and problem focused strategies. Emotion focused strategies include: thinking of the positive side, praying, mentally preparing for the worst, eating more to reduce tension, and taking one's mind off the topic. The latter example is described by Lazarus and Folkman (1984) as a defensive coping mechanism. Examples of problem focused coping include: considering several alternatives, seeking help from a professional, taking positive action, drawing on past experiences, and seeking further information. Data obtained in Chapter 4 indicated that patients endorsed the positive spirit coping style, however, analysis presented in this chapter indicates that constructs such as positive spirit and emotional defensiveness (i.e. inhibition) appear to be socially determined rather than personally determined. Nevertheless, patients did appear to change their coping strategy and engage in communication that inhibited the expression of their emotion.

In terms of responding to treatment, patients appeared to adopt a problem focused coping strategy (i.e. sought the assistance of a professional). Later in the process (i.e. when finished treatment), they seemed to engage in a problem focused coping strategies and commence seeking information and involvement in alternative therapies (i.e. again seeking help from professionals) and begin seeking further information regarding possible activities that they can become involved in. This latter strategy appears to include a combination of problem focused and emotion focused strategies. Following the exit of formal services, patients continue taking positive action and begin engaging in support groups, community services, and other activities. As described by research participants in the group and individual sessions, many of these later actions seem to occur as a result from a participants realizing that they were not coping as well as thought (e.g., onset of tears at unpredictable times), social interaction, and to be with similar others. Cancer patients may also seek assistance due to the finding that they are unable to slot back into their pre-cancer lives as easily as perhaps they had imagined.

The theory provides an adequate descriptive account of the coping strategies patients appear to have adopted throughout their experience of cancer; however, there are three main difficulties. Firstly, it is not always clear whether the coping strategy is emotion focused or problem focused. According to Lazarus and Folkman (1984) social support is a mixed strategy incorporating both emotion and problem focused coping. Secondly, when dealing with a life-threatening condition such as cancer the stressor is largely uncontrollable and the patients cannot themselves explicitly change this stressor. Thirdly, from an interventional point of view, it is difficult to assess the extent to which participants should be encouraged to adopt a problem focused versus an emotion focused coping strategy when dealing with the cancer experience.

In terms of using the principles of Lazarus and Folkman's (1984) theory in developing interventions, its principles appear to be limited to application at the individual level only. For example, determination of whether emotion focused or problem focused coping is adaptive or maladaptive requires an assessment of the individuals' appraisals and outcomes of such appraisals. Thus information shared by patient and psychologist could be used in developing strategies to reduce distress. When attempting to develop community level interventions, the theory does not appear to be particularly useful. Furthermore, the theory also lacks principles concerning when in the cancer process that interventions should be implemented and it does not suggest how such an intervention could be delivered at a community level. For instance, central to the theory is that individuals appraise stressors differently, thus without this individual knowledge one cannot propose an optimum way of coping at a community level. Furthermore, the theory does not incorporate the role that others play in the coping process. Such an account is essential in grounding the data produced in Chapter 6.

7.5.4 Conservation of Resources Theory

A final theory considered was the Conservation of Resources Theory (COR; Hobfoll, 2001, 1989, 1988). The theory extends beyond a focus on individuals' personal capabilities, and/or individuals' appraisals of stress towards an account that also incorporates the social context. Hobfoll (2001) describes the theory as one that integrates "... the individual-nested in family-nested in tribe, set in social context" (Hobfoll, 2001, p. 338). He uses the term 'tribe' as per the anthropological term to describe a group. In this account, a tribe extends beyond the immediate family and "includes formal and informal groups of friends, colleagues, organisations, and communities" (Hobfoll, 2001, p. 339). According to Hobfoll (2001, p. 339) attempts to separate individuals from the tribes to which they belong will result in incomplete accounts: "What I mean by individual-nested in family-nested in tribe is that attempts to separate any piece of this unit, without reference to the greater whole, will necessarily lead to limited predictive capacity..."

In this thesis, the failure to consider the social context within which patients lived and experienced cancer provided an inadequate explanation of the coping process. Incorporating the social process as was done in this study resulted in an entirely different account of the emotional inhibition construct. For instance, data emerging from this study indicate that tendencies to inhibit inhibition and the endorsement of a fighting spirit coping style may be socially determined.

The COR theory has potential applicability in terms of a) understanding how patients cope with cancer from diagnosis through to survival b) understanding the changes in patients coping approach (i.e. pro-activity and seeking of social support and involvement in other activities) c) informing individual and community level interventions.

Two basic constructs form the basis of the COR theory: resources and losses. According to Hobfoll (2001 p. 341) "... individuals strive to obtain, retain, protect, and foster those things that they value".

The COR theory predicts, for example, that stress occurs when valued resources are threatened with lost, actually lost, or lost following significant resource investment. Receiving a diagnosis of cancer not only threatens one's survival but also potentially leads to a loss of many valued aspects of patients' lives. Hobfoll (2001) lists up to 74 resources that he suggests are applicable to western cultures. Resources are 'defined as those objects, personal characteristics, conditions, or energies that are valued in their own right, or that are valued because they act as conduits to the achievement or protection of valued resources' (Hobfoll, 2001, p. 339). Individuals with greater internal and external resources are likely to gain further resources, whereas individuals with fewer resources are at risk of losing resources.

Evidence that resource loss is associated with increased psychological distress has been shown in studies involving traumatic events (Hobfoll, 2001). In an application of COR, Hobfoll (2001) describes the work of Norris and Kaniasty (1996; Kaniasty & Norris, 1995, 1993) who propose a 'support deterioration model'. Hobfoll (2001) suggests that in situations involving disaster or trauma, individuals and groups may respond by mobilising their resources which assists in minimising distress in the short term; however, these resources are not finite and if not replenished will dissipate with time. In this study, participants explicitly attempted to gain support from family and friends but in some instances were required to expend their own resources and did not receive support in return. During treatment, friends and family rallied around patients and provided an abundance of practical support.

In terms of coping with the treatment of cancer, patients generally reported positive accounts. For many patients the offering of practical support during treatment was considered to be a considerable resource. However, for some individuals, treatment was associated with losses particularly in terms of physical functioning. Those patients who appeared to be less affected by treatment may have had access to additional resources. For instance, some participants continued to work and may have had access to additional resources. Resources may have included continued financial security, interaction with peers (although these may have not related directly to the patient's cancer), use of valued skills and knowledge.

After treatment, many patients described the loss of support of family members and friends. Other losses also occurred at this time; for example, patients generally attended a final appointment with their specialist. Thus, a further loss was experienced when patients formally exited the health care system. This resource, for example, was a particularly valued resource as it had assisted them with maintaining their most basic and fundamental resource: survival.

Important in understanding distress according to the COR theory is that resource loss predicts further resource loss. For example, individuals who may have left their work due to the impact of treatment are likely to incur further losses. At this point, the researcher returned to the interview data to assess for evidence of the loss of valued resources.

7.6 Returning to data: Evidence of Resource Loss

7.6.1 Incidences of ‘Losses’

The researcher returned to the transcripts and assessed the data for further incidences of losses. Until this point, losses had been open coded within other categories such as spirituality and ongoing chronic ailments (see Chapter 6). Thus, data were subjected to further evaluation and other instances of loss (potentially coded under other categories) were selectively searched for and subjected to further analysis.

(i) Loss of work (opportunity to interact/use valued attributes)

Although many participants continued to work in their usual roles, some were forced to retire or resign due to physical limitations, or due to the intensity of treatment. In one case, a participant was forced to retire due to interpersonal criticism she received from colleagues at an alternative therapy college for engaging in traditional medical treatment.

They were oh you shouldn't be doing that in fact I was severely criticised and I never went back to the college. I could've gone on for the rest of my life, but retired. This was my decision. Everyone takes things at the time how they feel on the intuitive level and it felt right.

[Female: Breast]

Several participants stated that they missed their work. This appeared to be associated with a sense of loss of them being perceived as a valuable member that contributed to society in some way. A teacher, for example, some years after leaving her work reported that she ‘loved

her job' and misses this aspect of her life. This participant also described losses in terms of confidence across other domains or roles of her life: 'I think you set yourself up as a mother, as a teacher, as this and that and so lose [sic] confidence' [Female: Stomach].

(ii) Loss of interaction and loss of capabilities

Some participants also appeared to miss the interaction at work, and some missed the sense of capability or cognitive capacity one once had.

Retired, missed all that interaction. I couldn't function at that level anymore. I haven't got that concentration –I felt a bit like a dog chasing its tail.

[Female: Acute Myeloid Leukaemia]

This participant also described how she was never able to say goodbye to her work colleagues. She described receiving the diagnosis as a bit like being in a car-accident, one was not prepared. Her desk – with her work she was still doing – was just left.

She also noted that it was difficult to adjust to her change in role. This participant had been working in a high level position within a hospital and noted how one day she was working along side doctors and lawyers, and the next she was a patient. "One day dealing with doctors, lawyers, really knocked confidence" [Female: Acute Myeloid Leukaemia].

Another participant described losses in terms of her capabilities to perform home duties. For instance, she expressed frustration with her limitations in terms of what she could achieve each day (as compared with her capabilities prior to cancer).

I found that the time I was going through treatment, I think because I just focused so much on the treatment that I was really good. But the frustration I couldn't do what I used to be able to do and manage my day. Yes, my day, if I was home and managed to just get a meal on the table that was sometimes as much as I could achieve.

[Female: Non-Hodgkin's Lymphoma].

(iii) Loss of identity

For some patients there appeared to be a sense of loss not only in terms of their identity associated with their work role, but also on a personal dimension. This participant had given up her part-time job, and predominantly identified herself as a wife and mother, however, she describes a sense of not knowing where she fitted into society:

You're at home, you're isolated, you feel like you don't belong because when you work your part of a community a group, and you have a worth, a value placed on you. When you're at home your husband goes to work and your kids go to school and you think okay, where do I fit? It's difficult, and while you're still a mother and while you're still there for your kids and that's important you feel like I should be doing more and what should I be doing. I feel like I'm in between worlds, I feel like I'm here for the children, but I feel like my feet aren't on the earth anymore.

[Female: Non-Hodgkin's Lymphoma]

(iv) Other losses

Other losses were particularly profound for some head and neck patients who had faced significant changes in their appearance or ability to communicate clearly. One patient had lost the enjoyment to cook and enjoy food. She could only eat food that had been reduced to liquid and missed cooking. She also described another loss, most fundamental to being a human: simply to 'kiss my husband' [Female: Head and Neck].

7.6.2 Summary Losses

The data support an account of the cancer coping experience that is based on the concept of loss. For instance, all patients reported a loss of some kind. For some patients these losses were profound and indeed some losses appeared to result in further losses. Throughout the

interviews, patients reported experiencing losses in terms of economic resources because of hospital bills and losses of employment. These losses were linked with additional losses of a psychosocial nature (e.g., losses of colleagues and opportunities to interact) and psychological nature (e.g. losses in confidence). During treatment, patients reported losses in terms of cognitive capacity and physical abilities that in turn were associated with further losses. These losses appeared to be pervasive and reflected significant psychological and psychosocial losses (e.g., the individual's role and function in society).

7.6.3 Pro-activity and Willingness to Engage in Support Groups

As noted previously, some individuals who participated in the focus group (or individual sessions) acknowledged that they were not coping as well as they had previously thought (i.e. onset of tears at unpredictable times). Similarly, participants reported that they actively sought involvement in support groups, and accessed community services, to be with similar others and to gain social interaction and support. Although many participants reported that they had coped well with the treatment, during the research interview many patients attributed impairments in memory, difficulties concentrating and emotional distress to the treatment they received and did not consider alternative causes.

However, even for patients who reported that they coped well with the treatment, it is likely that considerable cognitive and physical resources would have been expended during this time, leaving few resources available for memory processes. The increase in use of community services and involvement in support groups may be associated with attempts to rebuild a supply of resources. Important in the context of understanding the change in participants' coping strategies in this study is that Hobfoll (2001, p. 353) proposes that:

... people are active participants in looking forward in their lives, considering their goals, evaluating obstacles and advantages that the environment is likely to offer, and acting to enhance their resources and limit their resource losses.

This account is consistent with the behaviour of participants. For instances, they described a willingness to engage in new activities and appeared to adopt a stance of pro-active behaviour in terms of assessing the environment for opportunities containing resources. Moreover, participants were willing to engage in a range of activities and continued to be involved in those activities if they met their goals.

7.6.4 From Theory to Intervention

Hobfoll's (2001) theoretical premises are relatively simple to apply to the development of both individual and community level interventions. According to Hobfoll (2001), resource loss is associated with increasing levels of distress, however, from an interventional point of view, resource gains become important in terms of reducing the impact of stress. Consistent with proposals in the health policy area and with the results of this research to date, other potential resources would include having access to quality medical care. Access to quality community services for cancer patients is yet another resource. Indeed, within this community resource the potential for a range of resources to be provided is endless. Indeed, Hobfoll (2001) proposes the concept of a 'resource caravan' and suggests that once resources are gained, other resources tend to cluster together. This concept is expanded upon in the final chapter of this thesis when a proposal, featuring resource caravans as its central feature, is described.

What becomes important then in terms of designing interventions is to determine the kinds of resources lost and to provide assistance in gaining those resources most highly valued. In this study, for example, the most valued support appeared to involve having the opportunity to meet with others with cancer. Potentially a range of supports could focus on improving the

support provided by families (i.e. allowing and endorsing cancer patients' expression of emotion and distress), educating friends, families, and health professionals concerning the losses cancer patients face when they exit formal treatment. Other programs such as assisting patients regain entry into work or have the opportunities to use their skills may also be potentially useful.

At an individual level, interventions would focus on identifying individuals at risk (i.e. low levels of resources); these resources may pertain to physical, cognitive or social resources. Central to Hobfoll's (2001) account is that those individuals with few resources are likely to be susceptible to further losses. Moreover, these are the individuals who are most at risk in terms of not seeking support (i.e. not utilising available services). For instance, Hobfoll (2001) suggests that individuals with limited resources become angry and withdraw for fear of losing further resources. Furthermore, individuals who lack adequate resources choose a defensive coping strategy in order to conserve any remaining resources.

In this study, patients who attempted to gain support from family and friends through emotional communication failed to gain further support (i.e. resources), thus they changed their coping strategy to one of emotional defensiveness (i.e., did not openly express how they were feeling). This change, however, did not occur due to an individual's propensity to be emotionally defensive (as is proposed in the dominant literature reviewed in Chapter 4) but instead occurred as a result of the actions of others in the patients' social world. According to Hobfoll (2001, p. 354) when an individual attempts to cope with a stressful situation (2002) "...[s]elf-directed behaviour plays a large role in this regard, but social and cultural influences often direct, limit or block efforts along prescribed corridors of action and response".

7.6.5 Conclusion

Whilst several stress theories provide an adequate account of some aspects of the results reported, the COR theory appears to provide a comprehensive and valid account of the results presented to date. In the next chapter, the issue of emotional expression will be explored further and a case-study longitudinal design will be implemented to assess an intervention focused on the expression of emotion via writing.

In the final chapter of this thesis, further application of the knowledge gained in this study will occur both at the research proposal and intervention levels. Societal expectations, particularly those involving concepts such as ‘positivity’ will be discussed in terms of representing a major barrier in reducing the impact of cancer and encouraging patients to utilise community services. As noted, a further detailed account of application of Hobfoll’s (2001) COR theory is provided in Chapter 10.

8 APPLICATION OF PENNEBAKER'S WRITTEN DISCLOSURE METHODOLOGY

8.1 Overview

As reviewed in Chapter 4, many studies have reported improvement in individuals' physical and psychological health following participation in written disclosure studies (for reviews see Sloan & Marx, 2004; Smyth, 1999). As noted in Chapter 4, the traditional experimental application of the Pennebaker's (1997) written disclosure paradigm involves participants in an experimental condition writing about their very deepest thoughts and feelings with respect to the most traumatic experience of their life. In the original written disclosure studies participants wrote for 4 days for 15 minutes per day; however, subsequent studies have varied the writing duration (from 10 to 30 minutes) and the overall time-frame (from 1 to 7 days per week or once a week for up to 4 weeks) (Pennebaker & Chung, 2007).

Standard and amended applications of the written-disclosure method

Standard instructions are typically adopted though some researchers to suit particular samples, contexts, and/or the foci of investigation have modified these instructions slightly. For example, the scope of writing topics has extended beyond the topic of one's most traumatic experience, and has included topics such as cancer, unemployment and HIV (for a review see Pennebaker & Chung, 2007). Variations such as introducing other experimental conditions whereby participants write about the benefits of trauma, or disease have occurred. Whilst the majority of studies have focused on outcomes such as physical and psychological health, other studies have investigated the effects of written disclosure on outcomes such as attitude change, working memory, creativity, motivation, life satisfaction, and school performance (Pennebaker & Chung, 2007).

8.2 How and Why is the Approach Therapeutic?

A number of explanations concerning why the written disclosure paradigm is effective in improving health have been proposed. According to Pennebaker and Chung (2007), however,

no single explanation accounts for the therapeutic effects of written disclosure with analysis possible at the social and biological levels and with a combination of factors/processes either inhibiting or facilitating its effect. Nevertheless, the main explanations proposed are summarised as follows. Initially, Pennebaker (1989, 1997) proposed a general theory of inhibition to account for the therapeutic effects of written disclosure. This theory was essentially based on the inhibition hypothesis. Researchers suggested this hypothesis was supported by research that showed that trauma victims who disclosed aspects of their trauma were healthier than those who did not disclose (Pennebaker & Susman, 1988).

A second explanation involved the application of learning theory, for example, phenomena such as 'classical conditioning' and 'habituation' were used to account for the effects. For instance, repeated exposure (disclosure writing) to the aversive emotional stimuli (traumatic event) weakens the link between the unconditioned stimulus (i.e., the emotional event) and the conditioned stimulus (i.e., the emotional experience) leading to extinction (i.e. habituation) of the conditioned response (i.e., the emotional reaction).

Recent accounts of the process of habituation include an additional cognitive element (Meadows & Foa, 1999). During the process of habituation individuals learn to acknowledge their emotion (i.e., they become cognisant) and then change in their understanding of the event and/or meaning assigned to the event. Other explanations offered centre around the psychoanalytic/experiential notion that the activation of emotional processes is a necessary requirement for psychotherapeutic change to occur. For example, Pennebaker and Chung (2007) report that participants asked to disclose factual information only do not benefit from written disclosure. They suggest that while the activation of emotional processes may be a prerequisite to producing therapeutic change, cognitive work is also required. In a variation of the traditional writing study, participants were required to express their trauma via

movement or in a second condition, via movement plus writing. Although both groups reported they felt healthier and happier following the study, only the latter group demonstrated improvements in physical health (Kranz & Pennebaker, 1995).

8.3 A to D Theory

Pennebaker's most recent explanation extends beyond the role of cognition and focuses directly on the process(s) of what occurs when emotions are translated into words and language, as per a typical writing study. According to Pennebaker and Chung (2007) verbally labelling an emotion can itself influence one's emotional experience. They propose that written disclosure results in reductions to the cognitive load allocated to the stressful event. In turn, these reductions result in enhanced self-regulation. They cite the following work to support this proposition:

- Audrain (1993) showed that subjects who were given a label to describe their emotional experience following reading a depressive story, reported higher life satisfaction than those who did not label their experience;
- Schwarz (1990) showed that cognitive processing involving the defining of internal feelings altered the feeling states themselves;
- Wilson (2002) demonstrated that focusing on emotions can improve the consistency between attitudes and behaviour; and,
- Feldman Barrett, Gross, Conner, Christensen and Ben Venuto (2001) showed that individuals who differentiate among various emotions are more likely to engage in effective emotion regulation strategies.

Pennebaker and Chung (2007) incorporate and extend these findings when proposing their A-to-D Emotion Theory. In this theory, the analogue signal (A) is analogous to Emotion, and the Digital signal (D) is reflective of language. Specifically, Pennebaker and Chung (2007)

suggest that the use of representative emotional labels in writing is linked with improved health outcomes. For instance, individuals who identify a moderate number of verbal labels (i.e., moderate representation as opposed to under- or over- representation) reflective of their actual emotion experience are more likely to make attributions and effectively plan for future actions. An excerpt from their paper describes the verbal labelling process and its hypothesised role in health.

...Once an experience is translated into language, however, it can be processed in a conceptual manner. In language format, the individual can assign meaning, coherence, and structure. This would allow for the event to be assimilated and, ultimately, resolved and/or forgotten, thereby alleviating the maladaptive effects of incomplete emotional processing on health.

Pennebaker & Chung, 2007, p. 28

8.4 Summary and Aims

Despite these theoretical proposals, presently no known study has tested them or indeed incorporated such knowledge into applications of the written disclosure methodology. For instance, to date no one has independently assessed whether participants when using a moderate level of emotion labels show a greater benefit from participation in a written disclosure study than individuals who use low or high levels of emotion labels. Furthermore, as is common with many efficacy studies, the majority of studies focus exclusively on symptom reduction without considering ‘why’ the approach is therapeutic.

Importantly, of two studies that have focused on the process of therapeutic change both report that the expression of some emotions may be deleterious. Lieberman and Goldstein (2006) found that the expression of anger predicted lower levels of depression and improved quality of life; however, the expression of anxiety and fear predicted higher levels of depression and poorer quality of life. Similarly, Pennebaker (1997) assessed data collected across six

expressive writing studies (N= 177) and found that the expression of positive emotions predicted improved health and well-being. These findings clearly challenge the proposition that the expression of negative emotion, alone, is beneficial therapeutically and such claims may lead to inappropriate applications of therapies involving the expression of emotion.

This study aimed to contribute to knowledge concerning why the writing process is therapeutic. Specific aims were to:

1. Assess for potential contextual factors involved in the therapeutic writing process by exploring the types (e.g. positive, negative), frequency, and nature of emotions expressed during the course of a four week writing intervention;
2. Monitor participants' levels of distress at various stages of a writing intervention, including pre and post intervention;
3. Assess for the stability or change in emotional inhibition and/or expression by comparing levels pre and post participation in the writing intervention;
4. Assess measures of emotional state throughout the intervention using state measures of anger, depression, anxiety and curiosity;
5. Assess participants' perspectives concerning the writing process; for instance, what kinds of positive/negative effects do participants ascribe to the writing process?

8.5 Method

8.5.1 Participants

Ten participants (6 females, 4 males) with a mean age of 55.10 years ($SD = 9.12$) participated in this study. At the commencement of this study, eight participants were in remission; one patient had received a diagnosis of recurrence approximately two weeks prior to commencing

participation in this study²² and the other patient had received a diagnosis of recurrence approximately 2 years ago following a period of 15 years in remission. Another participant received news of a possible recurrent diagnosis; however, the diagnosis was not confirmed until after this study had been completed. Diagnoses of participants included: head and neck (n=2); prostate (n=1); testicular (n = 1); stomach²³ (n = 1); lung (n =1); non-Hodgkin's lymphoma (1); Breast (n=2); Acute Myeloid Leukaemia (n = 1). The average time since diagnosis was 5 years although significant variation across the sample was evident (*Mean* = 60.20, *SD* = 52.78).

8.5.2 Differences between participants and non-participants

All participants, including those who participated in the research interview and survey, were offered the opportunity to participate in this study. Only 10/20 research interview participants, and 10/16 that provided survey data agreed to participate. Reasons for non-participation provided by non-participants included a lack of perceived need, time constraints due to work commitments, being too unwell to attend the University, or unknown (e.g., non-return of phone-call to the researcher).

Survey data obtained following the participation in the research interview were used to assess for potential differences between participants and non-participants. A table showing the results is provided in Appendix H. In summary, participants in this study had higher levels of distress than non-participants according to their scores on the Depression Anxiety and Stress Scales (DASS; Lovibond & Lovibond, 1995), the Impact of Event scale (IES-R; Weiss & Marmar, 1997) and the distress scale of Weinberger's Adjustment Inventory (WAI: Weinberger, 1991; Weinberger & Schwartz, 1990). Participants also tended to endorse higher levels of positive spirit, anxious preoccupation and fatalism according to the Mental Adjust to

²² The researcher encouraged the participant to withdraw from the study suggesting that the participant had other issues and concerns at this time. However, the participant was persistent that she wanted to participate in the intervention as long as she was well enough. The participant died a few weeks later.

²³ The original diagnosis was stomach, however, the cancer reoccurred in the ovary, hips and pelvis.

Cancer scales (MAC: Watson & Greer, 1988), and reported a higher need for harmonious relations as per the Lifestyle Defence Mechanism Inventory (LDM; Spielberger and Reheiser, 2002).

Participants had lower quality of life scores as measured by the Functional Assessment of Cancer Therapy, General (FACT-G; Cella, 1997, Brucker, Yost, Cash, Webster & Cella, 2005) and the Functional Assessment of Chronic Illness Therapy, Spiritual (FACIT-sp; Peterman et al. 2002) and religious involvement. Participants also had higher scores on the Courtauld Emotional Control Anger subscale (CES: Watson et al., 1983), lower scores on the Emotional Approach Coping scales (EAC; Stanton et al., 2002). In terms of meeting Weinberger and Davidson's (1994) criteria to be classified as having a 'repressive coping style', 50 % of participants met the criteria (5/10) and 50% of non-participants met the criteria (3/6).

8.5.3 Quantitative Measures

Distress and quality of life

Measures of distress in this study included the GHQ (Goldberg & Williams, 1988²⁴), the DASS (Lovibond & Lovibond, 1995) and the IES-R (Weiss & Marmar, 1997). Quality of life was assessed using the FACT-G and the 12 item spiritual well-being subscale (see Chapter 2).

Emotional regulation

Emotional inhibition was assessed using the anxiety, anger and depression scales of the Courtauld Emotional Control Scale (CES; Watson & Greer, 1983). For instance, in Chapter 5, it was shown that this measure was the most reliable and valid in terms of assessing the

²⁴ This measure was not included in previous chapters due to problems noted during the screening interview (see Appendix A). It was included in this study because it allowed an assessment of any change in reported stress from the screening interview to after the research interview.

tendency to inhibit emotion. Emotional expression and emotional processing were assessed using the Emotional Approach coping scales (EAC; Stanton et al., 2002).

State measures

The state scales of the State Trait Personality Inventory (STPI; Spielberger, 1979) were used to measure emotional states such as state-anxiety, state-depression, state-curiosity, and state-anger. The scale contains 40 items and respondents are required to respond to how they “‘feel now’ in response to 40 statements such as, ‘I am tense’; ‘I feel downhearted’; ‘I feel inquisitive’; ‘I feel like breaking things’. Items are scored on Likert scale from 1, ‘not at all’ to 4, ‘very much so’.

Written disclosure measures

A variety of measures have been routinely used by Pennebaker and colleagues to assess the impact of the written disclosure method. Pennebaker recommends that these measures be incorporated into research and amended as necessary to suit particular research projects (see <http://homepage.psy.utexas.edu/homepage/faculty/Pennebaker/questionnaires/WritingStudy.pdf>).

Weekly monitoring measures

Questions measuring the impact of the intervention on physical symptoms were included. These were based on research reported by Richards, Beal, Segal and Pennebaker (2000). For example, respondents were asked to indicate the extent to which they were currently experiencing a range of physical symptoms. These symptoms included: Racing heart, upset stomach, headache, dizziness, shortness of breath, cold hands, sweaty hands, pounding heart, nervous, sad, guilty, fatigued, constrained, anxious. Respondents indicated the extent to which these symptoms were present on a scale where 1 = ‘not at all’, 3 = ‘somewhat’, to 5 = ‘a great deal’.

End of intervention evaluation

A selection of questions used by Pennebaker in written disclosure studies were delivered to participants in a verbal format. Seven sought to understand the following: how much participants had thought about what they had written; how much they had talked to others about what they had written; to what degree they thought the sessions had a positive and/or negative long lasting impact on them; how happy they had felt since commencing writing; how sad they had felt since commencing writing; and to what extent the sessions were meaningful or valuable to them. Participants responded on a scale of 1 = 'not at all' to 7 = 'a great deal'.

Another question sought to identify whether participants, based on their experiences, would participate in such a study again. Response alternatives included: definitely yes, probably yes, don't know, probably no, definitely no. Additional open-ended questions sought to have participants elaborate upon how the sessions would influence them in the long run, identification of positive as well as negative effects, how other cancer patients might benefit from participation.

A final series of questions sought to evaluate the content of the intervention and to encourage participants to offer ideas and suggestions for future research. For example, participants were asked to assess the intervention content and approach in terms of the topics written about and the time allowed for writing. They were also asked to describe how they would like to see the research progress and what role they would like to play in this.

8.5.4 Qualitative measures

Frequency and nature of emotion words

Participants' writing samples were assessed for the frequency of use of positive and negative emotion labels. The labels included in the frequency counts focused on those provided in the Emotion Chart (see below).

8.5.5 Intervention and materials

Incorporating emotional labelling

To ensure that the psychotherapeutic approach was theoretically grounded, this application of Pennebaker's methodology incorporated recent advances in theory (i.e., the A to D Emotion Theory; Pennebaker & Chung, 2007). As previously noted, Pennebaker & Chung (2007) suggest that the written disclosure method is most effective in reducing distress when individuals have access to language and/or linguistic labels relevant and reflective of their emotional experiences. It was expected that individuals would differ in their ability or familiarity with different emotional states, and/or in having the language available to describe/label these emotions. According to Pennebaker and Chung (2007) if emotional events are under represented in the expression into language, elements of the emotional experience will continue to take up cognitive capacity and may cause distress. To optimise the use of emotional labelling in writing the program, participants were provided with a chart that displayed a range of linguistic labels reflective of the 6 primary human emotions described by Parrot (2001). A copy of this chart is provided in Appendix I.

Writing duration and topics

Participants wrote for 40 minutes on one occasion each week for a period of 4 consecutive weeks. Initially an 8 week intervention was proposed, however, upon consultation with the prospective participants, a reduced 4 week intervention was implemented. Patients felt more comfortable with being able to continue their commitment across a reduced time period.

Each week participants were provided with a different topic to write about. Topics focused on the discrete stages of the cancer experience. For instance, participants wrote about

diagnosis, treatment, awaiting results/visits with doctors, remission/last appointment with their doctor. Participants were encouraged to use the Emotion Chart to label their emotions. Pennebaker and Beal's (1986) standardised instructions were modified to reflect the incorporation of the A to D theory.

Prior to commencing writing, participants were provided with instructions; these were read by the researcher and then the printed instructions were left with the participant. Modifications to the instructions, to reflect the writing topics, and the incorporation of the A to D theory are noted in bold type face as follows:

I would like for you to write about your very deepest thoughts and feelings about **receiving a Diagnosis of Cancer. Try to label your feelings with the kinds of emotions you felt. If you are having trouble describing/labelling the emotions, use the chart provided.** In your writing, I'd like you to really let go and explore your very deepest emotions and thoughts. You might tie this event to your childhood, your relationships with others, including parents, lovers, friends, or relatives. You may also link this event to your past, your present, your future, or to who you have been, who you would like to be, or who you are now. **Remember to try to label your emotions and integrate these labels into your writing.** All of your writing will be completely confidential. Don't worry about spelling, sentence structure, or grammar. The only rule is that once you begin writing, continue to do so until your time is up.

Monitoring of distress

According to Pennebaker and Chung (2007), it is normal for individuals to experience some level of distress (and associated increases in arousal) during the writing exercise, particularly when writing about stressful experiences. However, it was not expected that this level of distress would be so extreme that a decrease in coping abilities with respect to a patient's cancer diagnosis would occur. Thus, embedded within the delivery of the intervention,

participants' levels of distress were routinely monitored. At the commencement of each session, the participants completed the GHQ and the DASS to assess their levels of distress and functioning over the preceding week. At the end of the writing session, patients completed the State scales and the physical symptom list.

Within this research protocol, specification to monitor distress and refer participants to a clinical psychologist was included. Any extreme increases in distress either as indicated by increases on these scales from baseline (i.e. survey data) or other indicators (excessive crying) were reported to appropriate ethics committees and the participant (s) referred for professional psychological assistance. This resulted in the reporting of one adverse event. The participant was also referred to a clinical psychologist, however, the participant did not make an immediate appointment and reported that she would meet with someone at a later time.

8.5.6 Procedure

Design

A case study longitudinal design with multiple assessments was implemented. This enabled a focus on intra-subject variation (i.e. within subject variation) as opposed to inter-subject (i.e. between subject variation) (Hilliard, 1993). The use of repeated assessments pre and post intervention and during the delivery of the writing intervention aimed to facilitate an in-depth understanding of the psychological processes/mechanisms potentially involved in the application of the Pennebaker and Beal's (1986) written disclosure methodology. These measures also enabled an assessment of the impact of the intervention on a range of measures reflective of distress, emotional state and quality of life. These data were complemented by an assessment of the frequency and nature of emotion labels contained in participants' writing samples.

Patient-centered evaluation

Within this design, and incorporating quantitative and qualitative measures a post interview attempted to evaluate patients' perceptions regarding the writing process. Finally, consistent with a Participatory Action Research framework (PAR; Elden & Chisholm, 1994; Kemmis & McTaggart, 2005; Susman & Evered, 1978), participants were also encouraged to provide critical feedback with respect to their involvement in the intervention. Participants were asked to identify future research objectives and/or outcomes they would like to see occur as a result of their research participation.

Timing of Assessments

As shown in Table 26, data were collected at 11 different time points. First, the General Health Questionnaire (GHQ; Goldberg & Williams, 1988) was included initially to screen patients in terms of their distress levels, however, as noted in Appendix A, this measure was found to be problematic in the cancer population, mainly due to potentially underestimating participants' levels of distress. This measure was then supplemented with the DASS. Nevertheless, the GHQ was included along with the DASS in subsequent assessments. Importantly, data relevant to the GHQ were collected at screening and following the research interview (i.e. baseline) enabling a potential assessment of any changes in participants' perceptions of distress following participation in the research interview.

Measures of distress, quality of life and emotion regulation were included at baseline and again following implementation of the intervention. There was a significant delay between baseline and the beginning of the intervention (9 months).²⁵ Importantly, additional assessments of distress as measured by the GHQ and the DASS occurred immediately prior to

²⁵ This delay was unavoidable due to a) awaiting potential further recruits before commencing the intervention and making decisions concerning the direction of the research project (please see Appendix A for a review) b) consideration of participant burden; for example, the full battery of measures required considerable time to complete and the researcher was concerned about the potential burden imposed on participants. Several participants had noted that the questionnaire took considerable time to complete.

the commencement of the intervention (i.e. Time 1 before). As shown in Table 26, assessments of the GHQ and DASS were continued throughout the intervention with participants instructed to answer the questions with reference to the preceding week. Furthermore, following the writing session, data relevant to the state measures (i.e. anxiety, anger, depression, curiosity) and physical symptoms was collected (see Time 1 After, Time 2 After, Time 3 After and Time 4 After). In these instances, participants were instructed to answer the questions with reference to their current state. Finally, data relevant to evaluating the research process and encouraging patient participation in future research were collected immediately following the last writing session (i.e. Time 4).

Table 26. Timing of Assessments

<i>Research Interview</i>		<i>Intervention: Weeks 1 to 4</i>								<i>Post-Int</i>
Screening	Baseline	Time 1 Before	Time 1 After	Time 2 Before	Time 2 After	Time 3 Before	Time 3 After	Time 4 Before	Time 4 After	Post Int
	GHQ	GHQ	S-ANX	GHQ	S-ANX	GHQ	S-ANX	GHQ	S-ANX	GHQ
	DASS	DASS	S-ANG	DASS	S-ANG	DASS	S-ANG	DASS	S-ANG	DASS
	IES-R									IES-R
	S-ANX		S-DEP		S-DEP		S-DEP		S-DEP	S-ANX
	S-ANG		S-CUR		S-CUR		S-CUR		S-CUR	S-ANG
	S-DEP		P.SYM		P.SYM		P.SYM		P.SYM	S-DEP
	S-CUR									S-CUR
	CES									CES
	EAC									EAC
	FACT-G									FACT-G
	SWB									SWB

8.6 Results

The results for this study are presented in two sections. In *Section A*, a summary of the results for each individual case is reported. A brief account of their demographic characteristics (i.e. type of cancer, time since diagnosis, remission status) and baseline levels of distress and quality of life is provided. For example, normative data described in Chapters 2 and 3 are used to assess the extent of distress and impaired quality of life observed at study entry (i.e. baseline) and comparisons are then made across the intervention (e.g., times 1 through 4) and post-intervention. Data relevant to baseline and post-intervention scores for total scores on the DASS, FACT-G, CES, EAC and IES are presented in this chapter, however, data relevant to assessments at the subscale score level are reported on in Appendix J.

When presenting these results, individual scores are cited and when relevant the reader is referred to the Appendix for authentication. Within the presentation of each case report, reference is made to whether or not the participant met Weinberger and Schwarz's (1994; Weinberger, 1990) criteria to be classified as having a repressive coping style. Data reported on in chapter 4 is used to make this assessment. In addition, specific changes in outcomes observed are reviewed and changes in the tendency to inhibit the expression of emotion, or use emotional approach coping are noted. This is followed by a description of the type, nature and frequency of emotional labels used during writing. Results relevant to the STPI state measures are also presented.

In *Section B*, an overview of the sample's results in terms of changes in distress is reviewed. This is followed by an attempt to highlight variables that distinguish participants who showed improvement on all outcomes (i.e. DASS, IES and FACT-G). As well as looking at the stability or change on emotion regulatory variables (e.g., emotional inhibition, emotional expression) and state emotion variables (anger, depression, anxiety and curiosity), other

variables relevant to Pennebaker and Chung's (2007) A to D Emotion theory (e.g., nature, type and frequency of use of emotion labels) and generic written disclosure measures are assessed. Observations concerning differences evident between repressors and non-repressors are also reviewed. Finally, consistent with the PAR approach, participants were encouraged to provide critical feedback on the writing process and to consider how they might be involved in future research and or application of these results.

8.7 Part A: Individual Case Reports

8.7.1 Participant 1

A 59 year old female with a diagnosis of acute myeloid leukaemia. The participant had been in remission for approximately 5 years and had received a diagnosis of recurrence a few weeks before commencing participation in the intervention. She had decided against conventional chemotherapy and was awaiting possible entry into an experimental trial if she was well enough. This participant did not meet Weinberger's (1990) criteria to be classified as a repressor. The participant had a current psychiatric diagnosis of bipolar disorder and had been receiving treatment from her psychiatrist for many years. At study entry, she had higher total DASS scores (62) than general population norms (Henry & Crawford, 2003) on stress (19) anxiety (15) and depression (28). According to Lovibond and Lovibond's (1995) severity ranges, she scored in the moderate range for stress and anxiety and the extremely severe range for depression.

With a score of 66 on the FACT-G, she had considerably lower quality of life scores (i.e. 20 points) than the general population with no chronic illness (i.e. mean 86.8, SD, 14.16 – see Brucker, Yost, Cashy, Webster & Cella, 2005). According to Webster, Cella and Yost (2003), a score difference of between 3 and 7 points on the FACT-G is clinically meaningful. Her scores on the IES scale were in the medium range according to the severity range described by Horowitz (1982). An intrusion score of 5 was in the low range and a score of 12

on the avoidance subscale was in the medium range. Criteria relevant to the hyper-arousal have not been published, although a score of 9 appeared high as the highest hyper-arousal score in published studies reviewed in Chapter 3 was 9. Compared with other study participants she had higher scores on the tendency to inhibit emotion (see Figure 9) and the tendency to use emotional approach coping (see Figure 10).

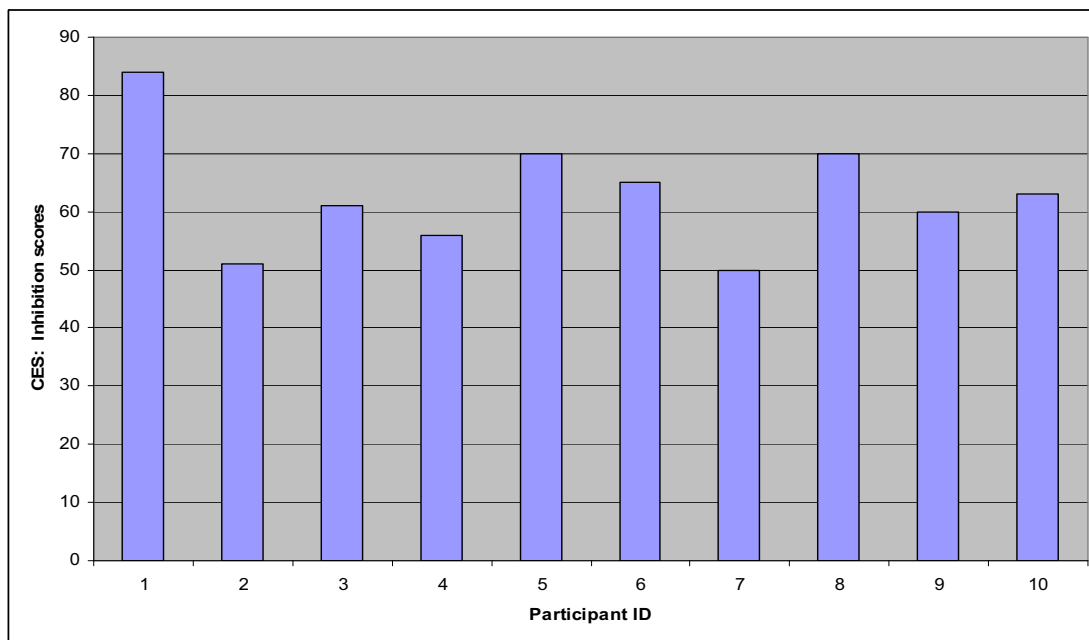


FIGURE 9
CES Emotional Inhibition Scores for the 10 Participants

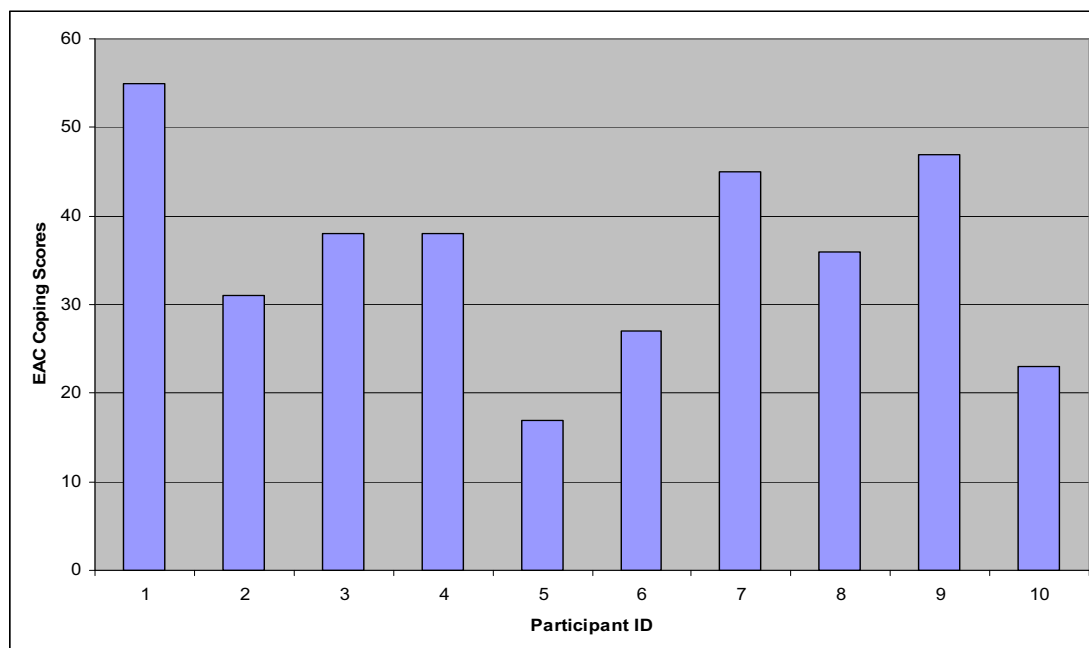


FIGURE 10
EAC Coping Scores for the 10 Participants

During the course of the intervention in which this participant was involved for 3 of the 4 weeks, her DASS scores showed decreases from baseline (62) to time 1 (23) but these increased at Times 2 (45) and 3 (64).

Frequency and type of emotion labels used in writing

The participant wrote according to the topics in Week 1 (Diagnosis) and Week 2 (Receiving Treatment), however, in Week 3 she did not write about the prescribed topic (i.e. Awaiting Results/visits with specialists). She wrote about her funeral arrangements and reflected on her decision not to have conventional chemotherapy. She also wrote about feelings of sadness at possibly not being around to be a part of her family's life. In the 3 writing samples, she used a predominance of negative emotion labels using a total of 19 labels over the 3 weeks she was involved²⁶. The researcher checked each writing sample for the use of the labels provided in the Emotion Chart. A summary of these results for all participants is shown in Table 9 of Appendix I.

Negative labels included: Sad, melancholy, negative, disappointment, anger and apprehension. Positive labels included: sentimentality, love, thrill, surprise, and *positive*²⁷.

As shown in Figure 11, scores on state measures of the STPI (Spielberger, 1979) fluctuated over the course of the intervention. Depression, anxiety and curiosity decreased from baseline to Time 1. Curiosity and anger decreased over the course of the intervention but anxiety and depression increased substantially in Week 3. These were the last records obtained from this participant as she died in Week 4.

²⁶ Although not part of the research protocol, this participant circled the words on the emotion chart and sometimes also wrote these down; these words were not included in frequency counts.

²⁷ Positive was not included on the emotion list, but 'optimism' was, therefore, the researcher included incidences of positivity in frequency counts. To be consistent the researcher also included references to negativity.

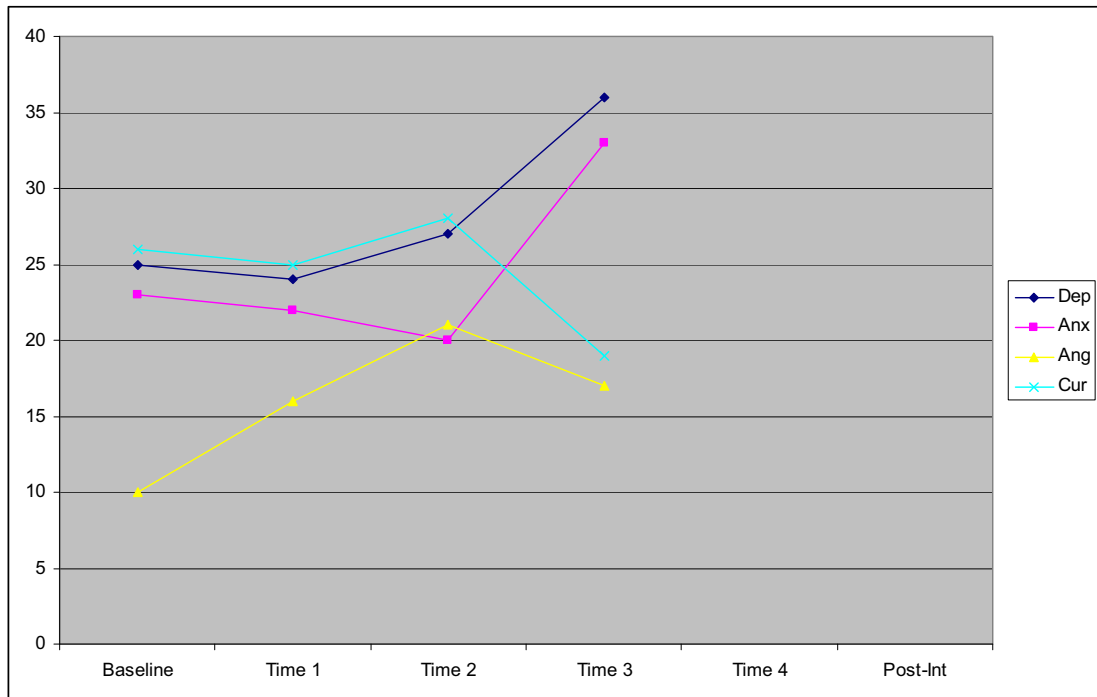


FIGURE 11
Participant 1: STPI Scores Baseline – Time 3

8.7.2 Participant 2

A 74 year old male who had been diagnosed with lung cancer 2 years prior to participation in the intervention. The participant had extensive surgery and chemotherapy and his lung function was reduced by 50%. He was in remission. According to the results obtained in Chapter 6, this participant had a likely diagnosis of dysthymia, however, he had not received any formal psychological or pharmacological treatment. This participant had met Weinberger's (1990) criteria to be classified as a repressor. As shown in Table 27 at baseline, the participant had only slightly impaired quality of life (i.e. down 3 points) as compared with healthy patients without chronic illness (Brucker et al., 2005). He also reported very low levels of distress (total score of 5) and was in the normal range according to Lovibond and Lovibond's (1995) severity range. At baseline, IES total scores (total 22) were in the high range. Scores on the intrusions (12) and avoidance (10) scales were in the moderate severity range. Compared with other participants, he reported moderate levels of emotional inhibition and emotional approach coping at baseline (see Figures 9 and 10).

TABLE 27
Scores on FACT-G, IES, EAC, CES
Baseline and Post Intervention and DASS Baseline, Time 1 and Post Intervention

<i>Participant</i>	<i>QoL</i>		<i>IES</i>		<i>DASS</i>		<i>DASS</i>		<i>EE</i>		<i>EAC</i>		<i>CES</i>	
	<i>Before</i>	<i>After</i>	<i>Before</i>	<i>After</i>	<i>Total</i>	<i>Time 1</i>	<i>Total</i>	<i>After</i>	<i>Before</i>	<i>After</i>	<i>Before</i>	<i>After</i>	<i>Before</i>	<i>After</i>
1	66		17		66	23	55		84					
2	83	78	22	18	5	27	31	12	51	26	45			
3	67	86	4	1	6	15	38	1	61	49	41			
4	97	100	2	13	5	8	38	1	56	41	51			
5	89	81	14	17	2	2	17	0	70	22	63			
6	94	87	18	19	0	12	27	10	65	27	57			
7	64	64	31	27	53	29	45	29	50	48	50			
8	77	84	20	19	28	26	36	20	70	43	63			
9	66	70	25	22	23	49	47	22	60	40	50			
10	94	90	4	19	7	9	23	3	63	18	65			

This participant's DASS scores increased from baseline (5) to Time 1 (27) and Time 2 (34) and showed decreases at Times 3 (21) and 4 (20). However, DASS scores at post-intervention (12) were higher than baseline scores. In particular, an increase in anxiety (from 0 to 5) and depression scores (1 to 4) was evident²⁸ (for confirmation see data reported in Appendix J), although scores were still below population norms. Post intervention, IES total scores decreased (1 point on avoidance and 2 points on intrusions), placing him in the low range for avoidance and moderate range for intrusions.

Scores on hyper-arousal increased by 1 point (i.e., to a total of 5). The participant showed decreases in the tendency to inhibit emotion (e.g., anger and anxiety but not depression) and use emotion approach coping (both expression and processing). As shown in Table 27, post-intervention, he reported decreased FACT-G scores. Impairments were noted in the following domains: physical (1 point); social and family wellbeing (3 points); emotional wellbeing (1 point) and functional wellbeing (1).

Writing and use of emotion labels

The participant wrote about his experiences according to the topics provided. He provided a factual account of his experiences. Over the 4 week writing period, this participant used the same amount of positive and negative labels: 6 positive labels and 6 negative labels. The labels used included: relief (Week 1); nervousness, amazement and relief (Week 2); stress, worry and joy (Week 3) and frustration, nervousness, relief, and happiness (Week 4).²⁹

As shown in Figure 8, scores on anger, anxiety and depression did not fluctuate to a great extent during the intervention. Nevertheless, an increase in anger was evident at Time 1

²⁸ Data relevant to providing results relevant to subscales of the DASS, IES, CES and EAC and FACT-G are provided in Appendix J.

²⁹ The patient did use additional labels "kick you in the guts" "lifted me" but these were not included in the frequency counts.

followed by reductions throughout the rest of the intervention. An increase in anxiety and depression was evident at Times 2, 4 and post-intervention. Post-intervention scores were higher on all state measures (excepting curiosity) than baseline levels.

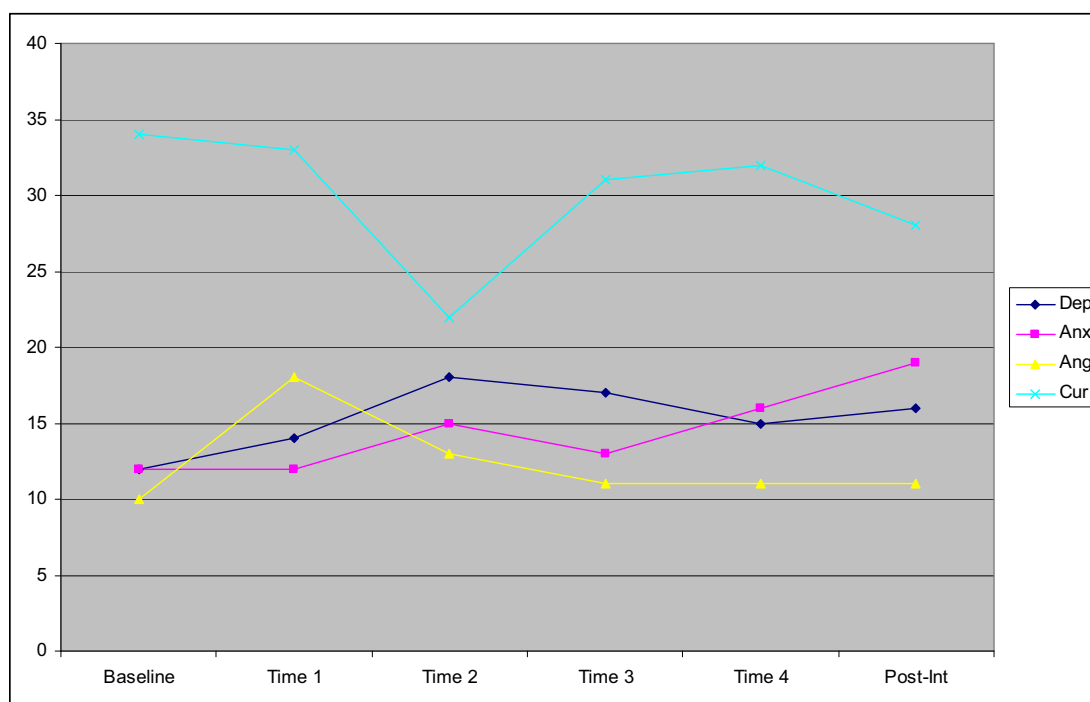


FIGURE 12

Participant 2 - STPI State Measures, Baseline to Post-Intervention

8.7.3 Participant 3

A 56 year old female with recurrent stomach cancer. She was originally diagnosed 15 years prior to participation in the intervention. At this time, she had surgery (e.g, 85% of her stomach was removed) and chemotherapy. She received a diagnosis of recurrence in the last 12 months with the cancer recurring in the ovary, pelvis and bones. She had undergone further surgery (hysterectomy) and chemotherapy. This participant met Weinberger's (1990) criteria to be classified as a repressor.

This participant had scores on the DASS that were considerably lower than the general population norms (6). Scores were also low on the IES (4), although quality of life scores were well below normal population norms (i.e., 20 points lower).

Across the intervention DASS scores increased slightly from baseline (6) to Time 1 (15) and showed slight variations across the intervention showing a decline post intervention. (1) Post-intervention scores were reduced on the IES (from 4 to 1) with decreases evident on intrusions (2 to 0) avoidance (2 to 1) and hyper-arousal subscales (1 to 0)³⁰. Decreases in emotional inhibition (anger, anxiety and depression) and increases in emotional expression (emotional processing and expression) were evident baseline to post-intervention. Quality of life scores post intervention showed a 19 point increase. Domains showing improvement included: physical (1 point), functional (9 points), social and family (6 points), and emotional (3 points).

Writing and use of emotion labels

The participant wrote according to the topics prescribed and included an account of both experiences (i.e. first and most recent diagnosis). Across the intervention the participant used 24 positive labels and 45 negative labels. The types of emotion labels used included: horror, worry, fear, guilt, anger, terror, disgust, upset, scared, guilty, surprise, delight and positivity (Week 1); fear, dread, mortification, worry, loathing, anger, frustration; amazement, excitement and positivity (week 2); worry, frustration, fear, fright, happiness, pride, positivity, elated (week 3); anger, horror, despair³¹, dread, worry, apprehension, happiness, delight, hope, elation, joy, positive, jubilation, ecstasy (Week 4) .

As shown in Figure 13 considerable variation was evident in state emotion scores across the intervention. Most notably, significant increases (i.e. scores doubled) in anger, anxiety and depression were shown in Week 1. Post-intervention scores on anxiety and depression (but not anger or curiosity) were slightly higher than at baseline.

³⁰ IES total scores are used as reference points due to a lack of studies publishing severity ranges including the hyper-arousal subscale.

³¹ The participant used the word devastation

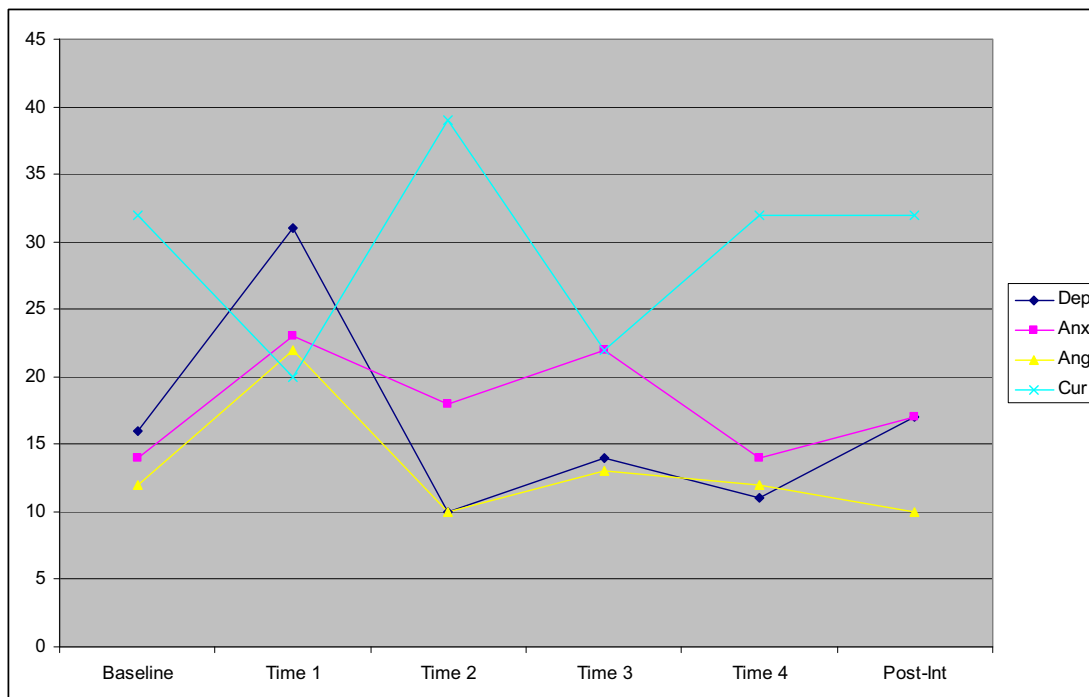


FIGURE 13

Participant 3: STPI State Scores Baseline to Post-Intervention

8.7.4 Participant 4

A 54 year old female who received a breast cancer diagnosis approximately 20 months prior to participating in the intervention. She had surgery and radiotherapy and was in remission. This participant met Weinberger's (1990) criteria to be classified as a repressor. As shown in Table 31, at baseline she reported negligible distress (DASS total, 5) and IES (2). DASS scores increased from baseline to Time 1 (8), Time 2 (20), Time 3 (8), Time 4 (6) but decreased post-intervention (1). Post-intervention scores increased on avoidance (2 to 10), intrusions (0 to 3) and hyper-arousal (0 to 1), shifting the participant from a low to a medium severity range.

As shown in Table 27, post intervention a 3 point increase in quality of life was observed; however, a closer analysis revealed that a point decrease occurred on the social and family well-being scale. Increases were observed on the following domains: emotional wellbeing (3 points) and functional well being (2 points). An increase in the tendency to use emotional approach coping was observed (for emotional processing but not expression). Overall, a

slightly decreased tendency to inhibit emotion was observed. Subscale scores revealed that an increase in the tendency to inhibit anger was evident.

Writing and use of emotion labels

The participant generally wrote about the topics provided, although similar issues were written about in each of the topics. She focused on relationship issues and communication issues with medical professionals. Within her account, 40 positive and 36 negative emotional labels were used. Examples included: anger, anxiety, disappointment, hope, love, happiness, contentment, pride (week 1); anxiety, disappointment, sympathy, worry, anger, resent, irritation, comfort, affection, elated, surprise, optimistic (Week 2); happiness, optimistic, elation, joy, relief 'short tempered', annoyance, anger, disappointment, sad (Week 3); anxious, nervous 'upset', surprised, positive, happy, relieved, joy, elation, optimistic (Week 4).³²

As shown in Figure 14, increases in anger and anxiety were observed at Time 2. Little variation on depression was evident throughout the intervention, although at post intervention depression and anxiety increased. Scores on curiosity decreased at Times 1 and 2 and increased very slightly throughout the rest of the intervention. Scores on anger remained stable from Time 3 to post-intervention.

³² Note the participant did not always use particular emotion labels but instead used terms such as 'very cross', 'very tense', 'on edge'; these were included in frequency counts.

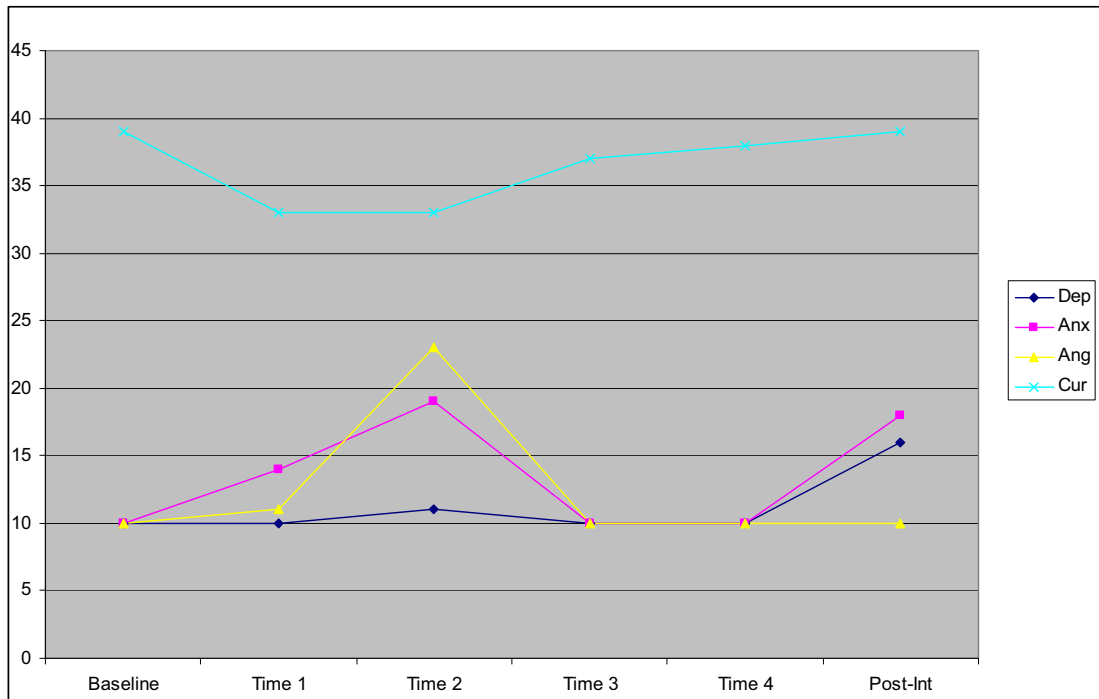


FIGURE 14

Participant 4, STPI Scores Baseline to Post-Intervention

8.7.5 Participant 5

A 51 year old diagnosed with testicular cancer had been diagnosed approximately 7 years ago and was in remission. This participant met Weinberger's (1990) criteria to be classified as a repressor. As shown in Table 27, at baseline he reported very low levels on all DASS measures (i.e. total of 2) and scores on the FACT-G were 3 points higher than healthy individuals with no chronic illness.

Levels of emotional approach coping were low relative to other study participants and levels of inhibition were moderately high (see Figures 9 and 10). At baseline, scores for the IES indicated that he had moderate levels of avoidance (11), low levels of intrusions (4) and hyper-arousal (1).

Across the intervention very little variation in DASS scores was observed, nevertheless, a decline at post-intervention was evident but negligible (i.e. from 2 to 0). Post intervention scores indicated a decrease in FACT-G scores; a 7 point decrement was observed on physical

and functional wellbeing along with a 1 point decrement on the social and family wellbeing scale. An increase in total IES scores was observed with a considerable increase in avoidance (11 to 17) and intrusions (1 to 3). Hyper-arousal decreased by 1 to 0.

An increase in the tendency to use emotional approach coping (increase in both expression and processing) was indicated, however, scores were still lower than other participants. A decreased tendency to inhibit anger and depression was evident, but an increase in the inhibition of anxiety was observed.

Writing and use of emotion labels

The participant provided a factual account of his experiences in a fairly detached manner; he used the analogy of having a car fixed. The emotions that were expressed during the writing appeared to be relevant to what his partner was feeling rather than himself. Throughout the intervention period he used 7 positive labels and 22 negative labels. These included: agitated, annoyed, negative, helpless, melancholy, frustration (week 1); positive, relief, jubilation, happiness, fearful, panic, useless, frustrating, '*nerves were jangling*', (Week 2); worry, frustration, terror (Week 3); helpless, sadness, positive, enjoyment (week 4).

As shown in Figure 15, slight increases in anger scores were observed but these scores decreased and remained stable through to post-intervention. Increases in curiosity and decreases in depression and anxiety were observed at time 3. These remained stable with slight increases in anxiety and depression, and decreases in curiosity as compared with baseline levels.

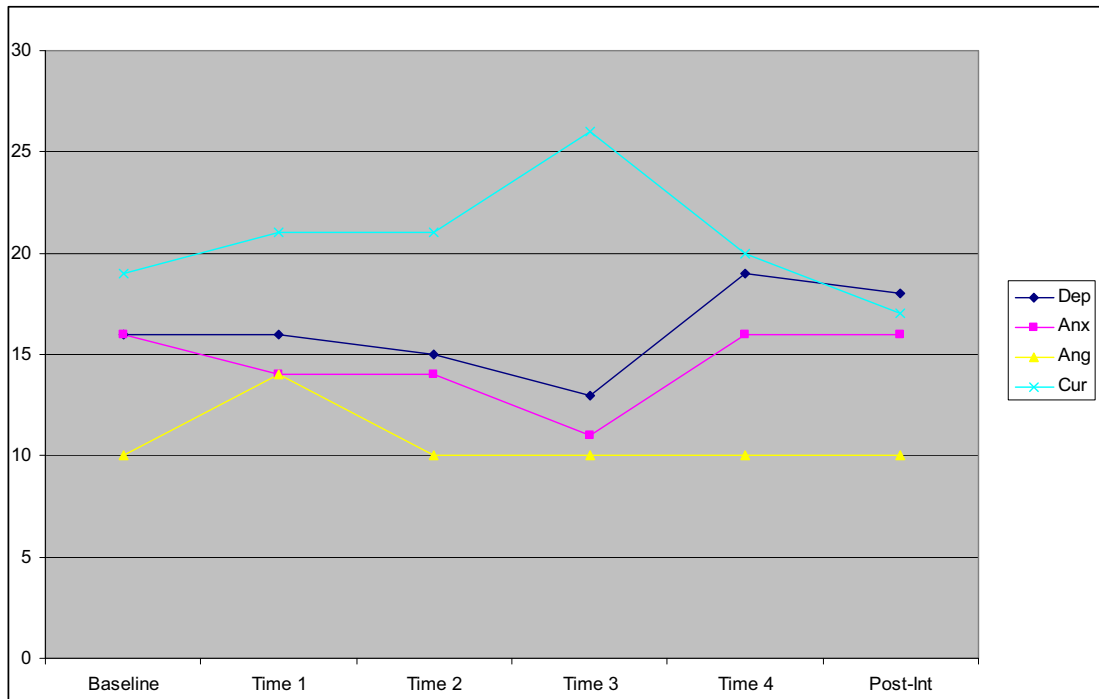


FIGURE 15

Participant 5: STPI Scores Baseline to Post-Intervention

8.7.6 Participant 6

A fifty one year old female who received a diagnosis of breast cancer 2 years prior to participation in the intervention. She had surgery for the removal of a tumour and lymph glands; she also received chemotherapy and radiotherapy. The participant was in remission. She met Weinberger's (1990) criteria for classification as a repressor. As shown in Table 27, she reported an absence of distress on all domains of the DASS (score = 0). But a score of 18 on the IES was indicative of a moderate level of symptoms. A score of 14 on the avoidance scale was in the moderate severity range, and a score of 4 on the intrusions subscale was in the low range. She reported scores 8 points higher than the healthy population without chronic illness (Brucker et al., 2005).

DASS scores increased at Time 1 (12) and slight variation across the intervention increasing slightly at post-intervention (DASS = 10) compared with a baseline of 0. There was no change in emotional approach coping scores, but increases in expression and decreases in processing were noted. A decrease in the tendency to inhibit anger and depression was

observed but an increase in the tendency to inhibit anxiety was observed. Post-intervention IES scores showed a one point increase but an increase in intrusions (4 to 8) and a decrease in avoidance (14-11) was evident. Scores on the FACT-G declined from baseline to post-intervention. Specifically these decrements were in the following domains: social and family well-being (3) emotional wellbeing (2) functional wellbeing (2).

Writing and use of emotion labels

The participant generally wrote according to the prescribed topics. She used 7 positive labels and 20 negative labels. Examples included: passion, confident, shocked, numb, uneasiness, apprehension, nervous (Week 1); fear, shock, sad, worry, positive and confident (week 2); enjoy and positive (week 3); anger, anxious, nervousness, frustration, comfort and upset (week 4). As shown in Figure 16, state emotion scores showed little variation across the intervention. Most notable was a lack of change in state anger. Depression shows slight decreases at time 2 but anxiety and depression scores increased over the course of the intervention remaining higher than baseline levels. Curiosity also decreased post intervention.

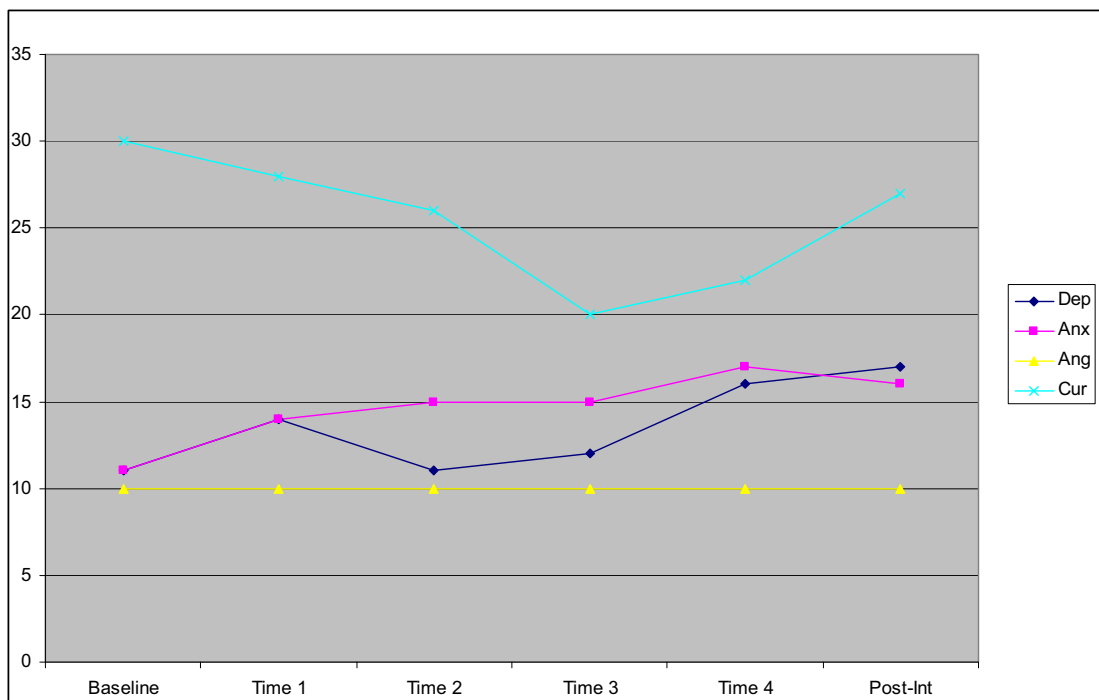


FIGURE 16

Patient 6: STPI Scores Baseline to Post-Intervention

8.7.7 Participant 7

A 61 year old male who received his diagnosis of throat cancer in 1996. He was in remission. He had extensive surgery and radiotherapy that had resulted in changes in his appearance. At base-line, he had high levels on all scales of the DASS (Total 53). For example, according to Lovibond and Lovibond's (1995) severity ranges he scored in mild range for stress, extremely severe range for anxiety and moderate range for depression. On the IES, he scored in the high range (31). On avoidance (12) he scored in the moderate range and on intrusions (19) in the high range. He also reported high levels of hyper-arousal (9). At baseline, he reported relatively high use of emotional approach coping strategies and moderate scores on the tendency to inhibit emotion were indicated.

Over the course of the intervention, he showed a decrease in DASS scores from baseline to time 1 (29) with scores finishing at Time 1 levels post-intervention (29). Scores on the DASS post intervention indicated that he was in the normal range for stress and depression but in the moderate range (rather than extremely severe) for anxiety.

There was no change on FACT-G scores which were considerably lower (i.e., 22 points) than the general healthy population without chronic illness. Post intervention he showed a slight increase in the tendency to use emotional approach coping but no change in the tendency to inhibit emotion was indicated. Scores on the IES decreased pre to post intervention by 4 points on avoidance, but there was no change on intrusions. Scores on hyper-arousal decreased slightly (11 to 9).

Writing and use of emotion labels

This participant appeared to have a vivid and detailed recall for the specific events surrounding his diagnosis and treatment, however, at each session he requested additional time. The researcher allowed a maximum of 10 additional minutes.

He used 5 positive emotion labels and 19 negative labels. These included: compassion, negative, anguish, despair, grief (Week 1); sadness, hopeless, despair, shock, fear, elation (week 2); embarrassment, shock, hopeless, despair, (Week 3); hate, depressed, guilty, helpless, surprise, amazing, positive (week 4). As shown in Figure 17, he showed increases in anger and curiosity from baseline to time 1 and decreases in anxiety and depression.

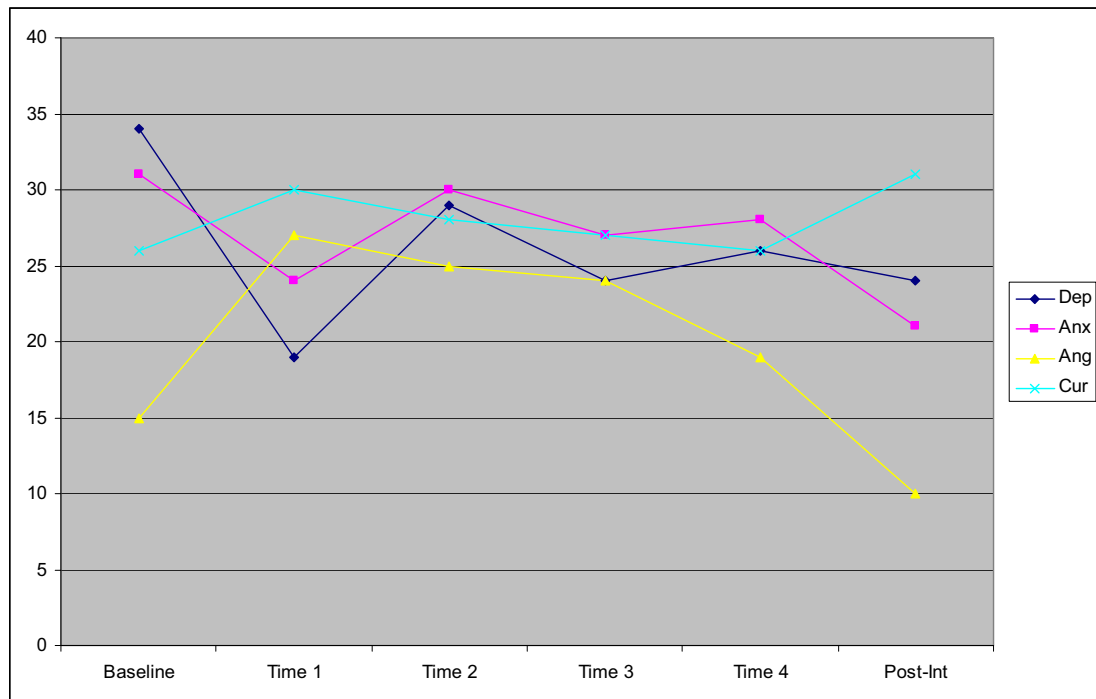


FIGURE 17
Participant 7: STPI Scores Baseline-Post-Intervention

8.7.8 Participant 8

A 52 year old female had been diagnosed with mouth cancer 5 years prior to participating in the intervention. She had extensive surgery and radiotherapy resulting in severe impairments (i.e. inability to eat by mouth and impaired ability to communicate) and disfiguration.

Initially, the cancer was diagnosed following a traumatic incident that occurred overseas. She had surgery abroad and when returned to Australia, some cancer was still present. At the time of participation in the intervention she was in remission, however, during the intervention (Week 3) her dentist found a further growth and she had a biopsy performed in Week 4.

According to results reported in chapter 6 this participant had a probable diagnosis of social phobia.

At baseline, total DASS scores were moderately high (28), and comparison with normative data indicated that levels of stress and depression were in the normal range but levels of anxiety were in the moderate range. At baseline she reported reduced quality of life (i.e., 9 points lower than a healthy population without chronic illness), and IES scores were in the high range at 20 with scores on intrusions (12) and avoidance (9) and hyper-arousal (5) in the moderate range.

During the course of the intervention, DASS scores decreased in Week 2 (26) but showed a substantial increase in Week 3 (99) followed by decreases in Week 4 (17) and post intervention (20). FACT-G scores increased post-intervention by 7 points with improvements shown in the following domains: social and family wellbeing (3), emotional wellbeing (1) and functional wellbeing (3).

A one point reduction on total IES scores was evident; a closer analysis revealed a two point decrease on avoidance and a 1 point increase on intrusions. Scores post intervention also showed an increase in the emotional approach coping scale scores and decreases in the tendency to use emotional inhibition.

Writing and use of emotion labels

The participant wrote a detailed account with respect to each of the writing topics. In Weeks 3 and 4, she also wrote about her current experiences. She used 7 positive emotion labels and 19 negative label including: terror, shock, helpless, anger, frustration, fear, worry, pride, surprise (Week 1); fear, positive, cheerful, sadness, happiness, (week 2); fear, surprise, sadness, shock, positive, hope (Week 3); anger, regret, positive (Week 4). As shown in

Figure 18, there was a decrease in anxiety and depression from baseline to time 1, however, anger, depression and anxiety increased at Time 3 and 4. Anger increased to time 3 and showed steady declines to baseline levels. Anxiety and depression remained high remaining slightly higher than at baseline.

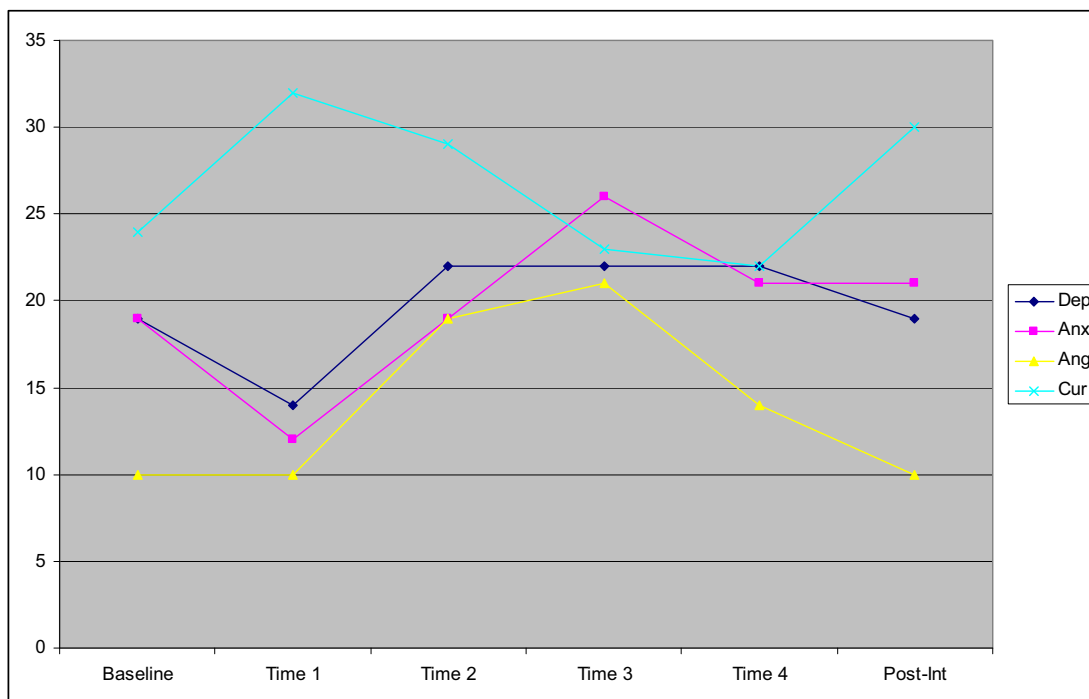


FIGURE 18

Participant 8: STPI Scores Baseline to Post-Intervention

8.7.9 Participant 9

A 44 year old female with non-Hodgkin's lymphoma received the diagnosis approximately 3 years ago. She was in remission. This participant met the criteria for a mood disorder according to the results reported on in Chapter 6. The participant was currently receiving pharmacological treatment for her psychological disorder. At baseline, DASS scores were higher than population norms on stress and anxiety (not depression) but all were in the normal range according to the Lovibond and Lovibond's (1995) severity ranges.

According to the Horowitz (1982) severity ranges, total scores on IES total scores were in the high range and medium range for intrusions (11) and avoidance (14). Scores on the hyper-

arousal subscale were very high (13). At baseline, the participant reported impaired quality of life (down 20 points from healthy population).

Across the intervention DASS scores increased from baseline (23) to Time 1 (49) but decreased post-intervention (22). Slight decreases on intrusions (1 point) and avoidance (2 points) were evident. A five point decrease on the hyper-arousal scale was observed. Post intervention data revealed a decreased tendency to inhibit emotion (all scales) and increased emotional expression (emotional processing no change). A four point improvement in quality of life scores was evident with increases on physical wellbeing (4), emotional wellbeing (1), and functional wellbeing (1). However, a decrement of 2 was observed on the social and family wellbeing subscale.

Writing and use of emotion labels

The participant wrote according to the prescribed topics. She used 12 positive labels and 44 negative labels. These included: anger, fear, shock, apprehension panic, fear, resent, relief (Week 1); relief, guilt, sadness, apprehensive, frustration (Week 2); panic, anxiety, fear, frustration, fright, terror, panic, anger, rejection, optimism, hope, love, joy, elation, victorious (Week 3); positive, enjoy, loneliness, frustration, depressed, irritation (Week 4). As shown in Figure 19, scores on anger and anxiety increased from baseline to Time 1 and decreased at Time 2. All state emotion scores were lower at post-intervention than baseline.

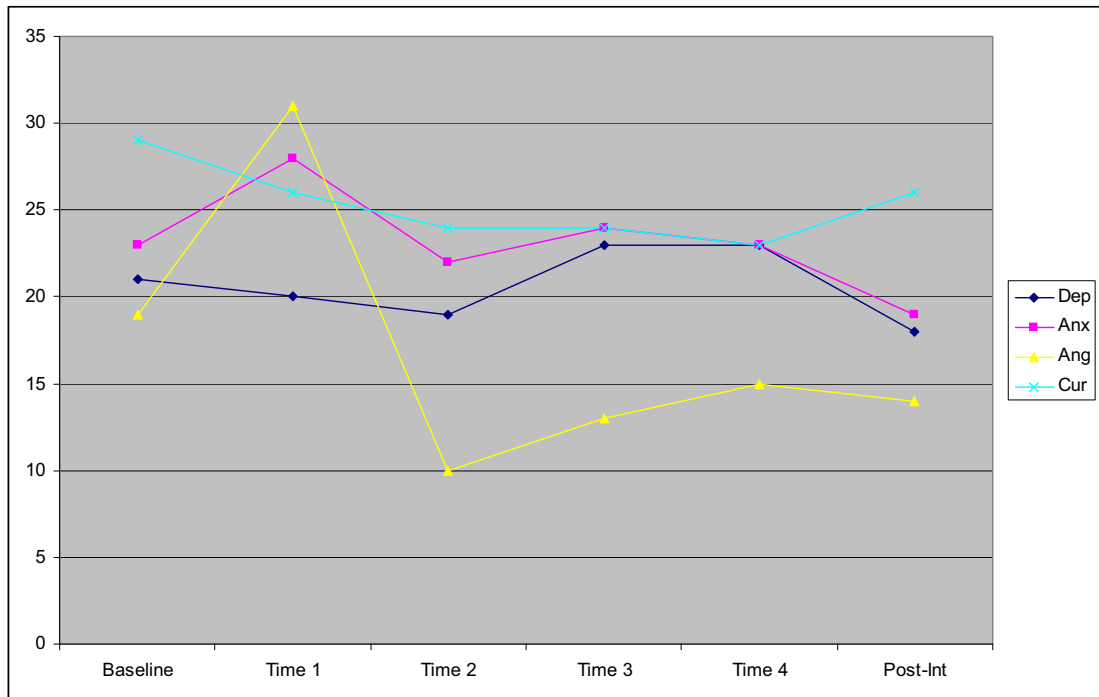


FIGURE 19

Participant 9: STPI Scores Baseline to Post-Intervention

8.7.10 Patient 10

A 71 year old with prostate cancer, had surgery followed by hormone therapy. He was in remission. This participant did not meet Weinberger's (1990) criteria to be classified as a repressor. At study entry he had higher levels of quality of life as compared with healthy norms without chronic illness (up 6 points), scored very low on the IES (4) and DASS (7). Compared to other participants, he scored very low on emotional approach coping measures and relatively high on the tendency to inhibit emotion.

Across the intervention, DASS scores increased from baseline (7) to Time 1 (9) showing declines at post-intervention (3). Scores on the FACT-G showed a decrease of 9 points. Specifically the domains affected included: social and family wellbeing (4) and emotional well-being (1). There were improvements on functional wellbeing (2). He showed a decline in already low scores on the tendency to use emotional approach coping, and whilst he showed a decrease in the tendency to inhibit anger, he showed increases in the tendency to

inhibit anxiety and depression. Post-intervention IES scores increased substantially placing him in the high range according to Horowitz's (1982) criteria. Avoidance increased from 3 to 7 and intrusions from 1 to 12 and hyper-arousal increased from 2 to 4.

Writing and use of emotion labels

The participant provided a relative factual account of his experiences. He used 4 positive emotion labels and 9 negative emotion labels. Labels included: shock and worry (Week 1); optimism and worry (Week 2); depressed, shocked, worried and nervous (Week 3); elated and relieved (Week 4). As shown in Figure 20, little variation in scores was evident across the intervention. Some slight variation in anxiety was observed with increases at Time 1 and Time 4.

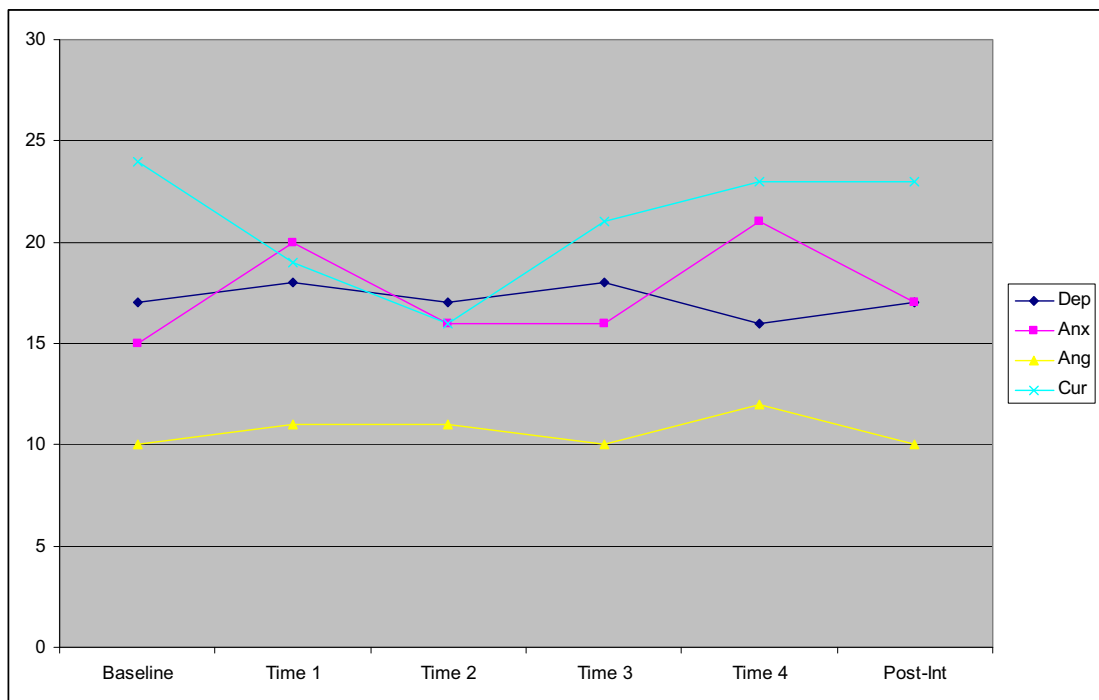


FIGURE 20

Participant 10: STPI Scores Baseline to Post-Intervention

8.8 Part B. Process Evaluation and Intervention Outcomes

8.8.1 Patients' levels of distress: DASS and GHQ

Results indicated that 7 of the 9 participants showed decreases in DASS scores from baseline to post-intervention. As shown in Figure 21, when comparing Time 1 scores with post-intervention scores, 8/9 participants showed a decrease in scores on the DASS.

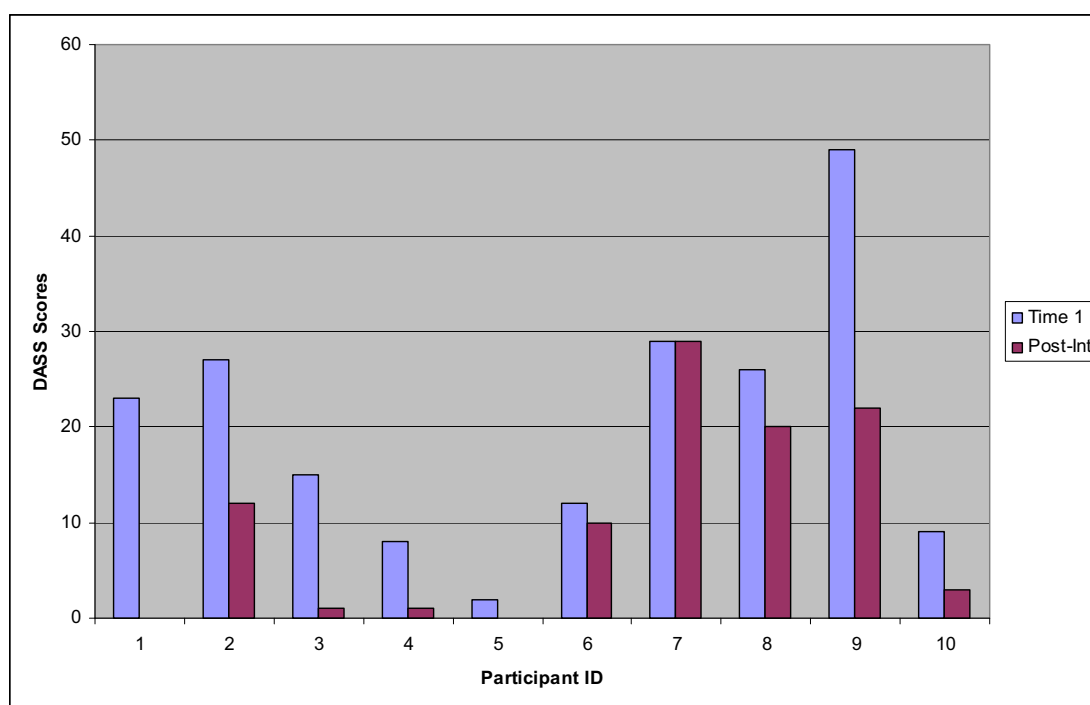


FIGURE 21

DASS Scores Time 1 to Post Intervention

Decreases in distress scores were also observed when plotting scores on the General Health Questionnaire (GHQ; Goldberg & Williams, 1988) using an additional time point. For instance, all participants completed the GHQ³³ at screening, prior to participation in the intervention (Time 1), Times 2, 3, 4 and post-intervention. As shown in Figure 22, scores on the GHQ show a general decline from screening to post-intervention. Moreover, a decrease in

³³ The GHQ was used at screening but was later replaced with the DASS. When screening was conducted, the researcher noticed a disparity between patients' behavioural responses (i.e. crying being upset) and their responses on GHQ items. Also note that the items have been scored using 1 – 2 – 3 – 4 values

distress occurred between screening and baseline for 7/10 participants. The 3 exceptions were participants 2, 9 and 7 for which scores increased. The peaks observed in this figure reflect Participant 1's increasing levels of distress concerning her possible death. At Time 3, Participant 8 received news of a possible new growth for which she required a biopsy.

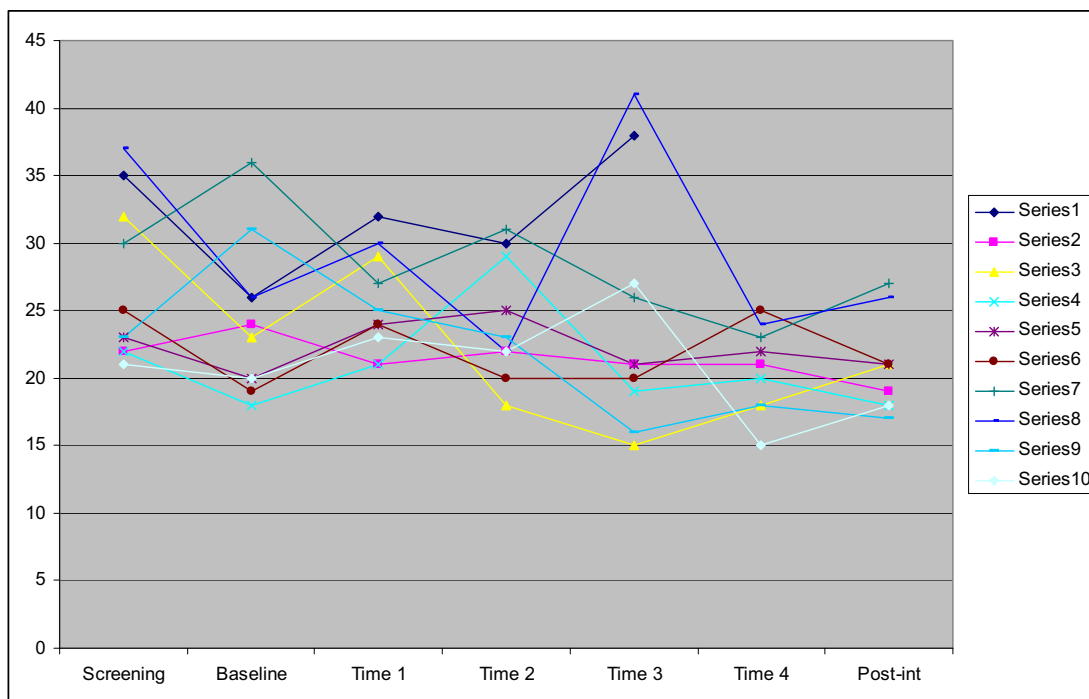


FIGURE 22
GHQ Scores Screening to Post-Intervention

8.8.2 State measures

The state measures were not included as specific outcome measures and instead they were used to track levels of distress over the course of the intervention. Any marked changes that were not resolved (i.e. did not decrease in the subsequent week(s) of the intervention) were an indicator to the researcher that the intervention was having a potentially adverse impact on the participant. Nevertheless, the data tracked provided some insight into possible mechanisms associated with therapeutic benefit. For example, the results indicated that 3 of 9 participants showed therapeutic benefit on all 3 outcome measures (i.e. IES, DASS, and FACT-G). A fourth participant showed decreases on IES and DASS but scores on the FACT-G remained the same.

As shown in Figure 23, in each of these cases (i.e. participants 3, 7 and 9) there was a marked increase in the expression of anger at Time 1. Similarly, participant 8's scores showed a marked increase in anger between Times 2 and 3. Participant 4 also showed an increase in anger scores at Time 2. Unlike the scores for participants 3, 7 and 9 where a steady decline in anger scores occurs a flattening of scores was evident. This finding is consistent with the results reviewed for this participant. For instance, she showed an increase in the tendency to inhibit anger at post-intervention.

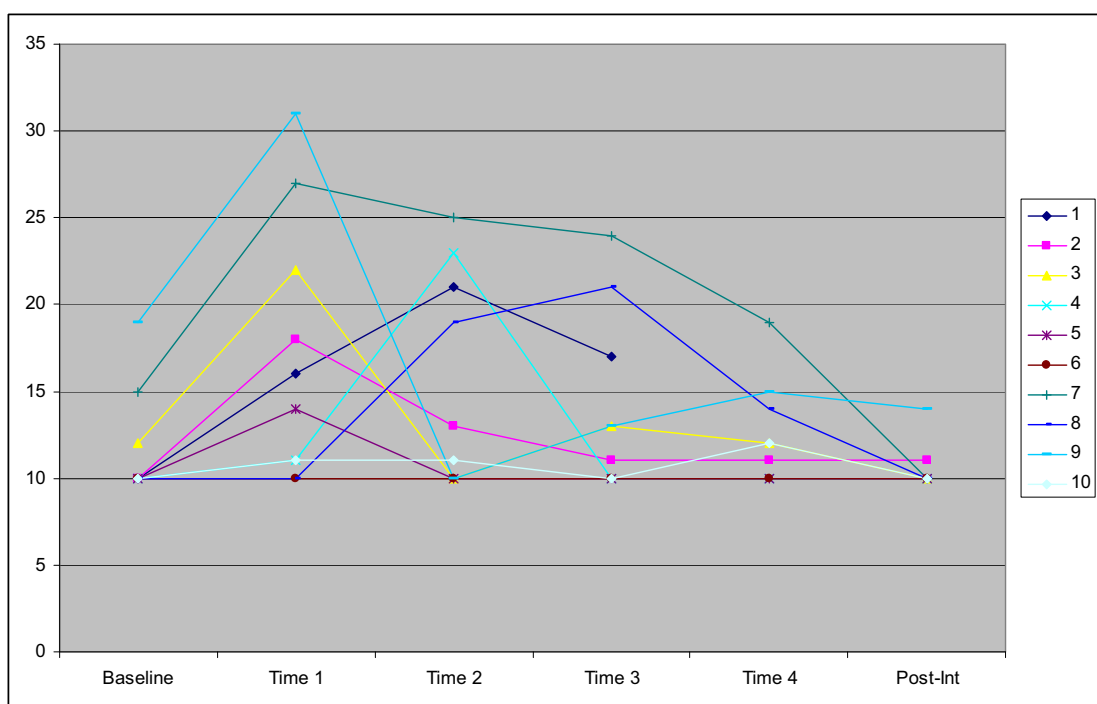


FIGURE 23

State Anger Scores for all Participants from Base-line to Post-Intervention

Potential hypothesis – lack of fluctuation in emotion states across the intervention

Other potential hypotheses can be derived from looking at the pattern of scores on the anxiety and depression scales across the intervention period. For at least three participants, scores on anxiety and depression did not show a tendency to fluctuate as would be expected following writing. As shown in Figures 24 and 25, participants 2, 5 and 6 have relatively flat scores across the entire intervention. It is interesting to note at this point that these participants met Weinberger's (1990) criteria to be classified as having a repressive coping style.

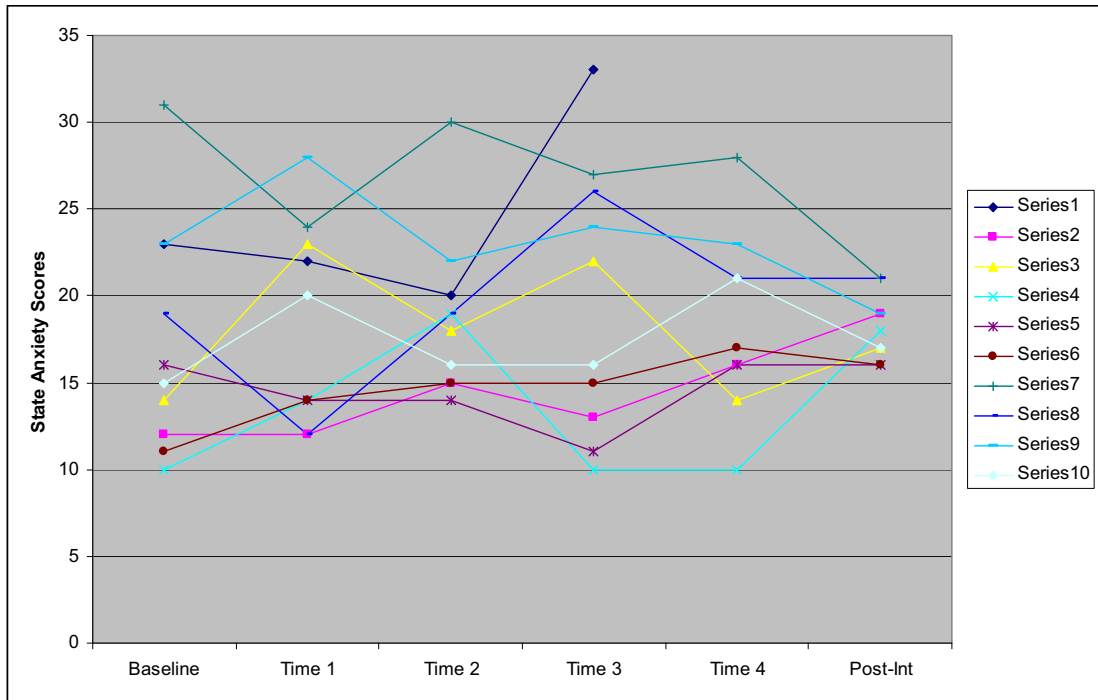


FIGURE 24

State Anxiety Scores Baseline, Time 1 – Time 4, and Post-Intervention

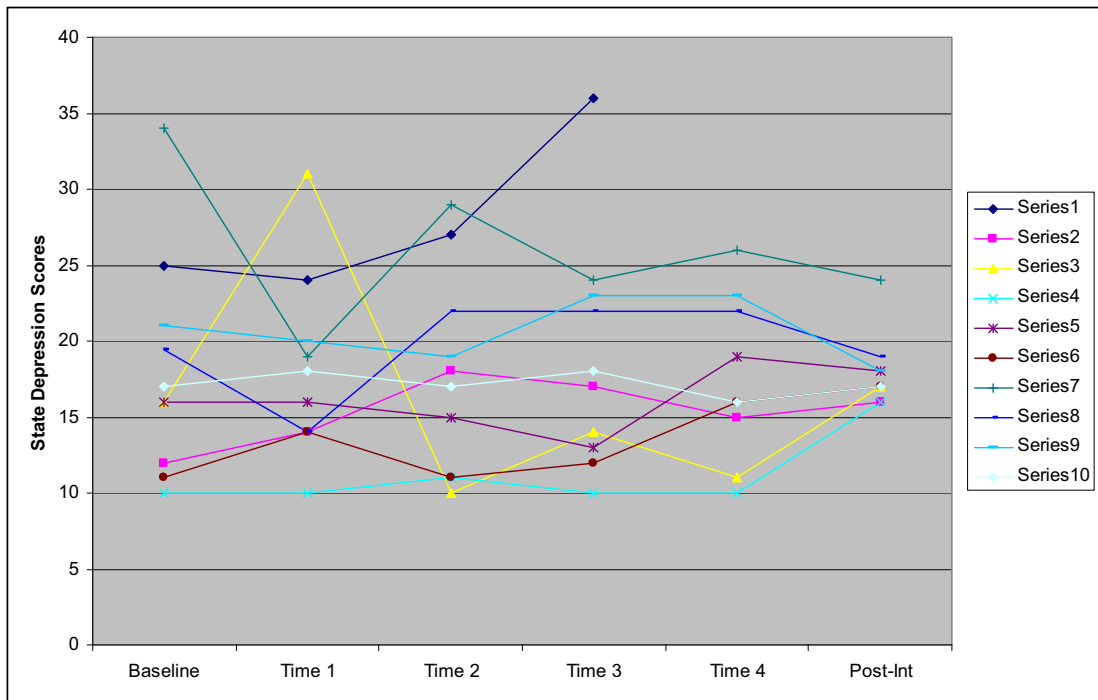


FIGURE 25

State Depression Scores Baseline, Time 1 – Time 4, and Post-Intervention

8.8.3 Frequency and nature of emotions expressed

As reviewed, patients' writing samples varied with respect to the frequency that they used emotion labels; some participants used very few labels whilst others used moderate or high levels of emotion labels. Generally, only those labels that appeared in the Emotion Chart were included in the frequency counts. However, at times exceptions were made and these were documented within each case study report.

Unfortunately, Pennebaker and Chung (2007) do not prescribe how many labels are likely to be compatible with low, moderate and high use of emotion labels. Thus, an attempt to apply cut-offs arbitrarily may provide misleading results. Nevertheless, an effort to explore the kinds of variables that might be associated with therapeutic benefit is provided. Shown in Table 28 are the results for each of the post-evaluation variables included in this assessment

TABLE 28
Post-Intervention Evaluation

	1	2	3	4	5	6	7	8	9	10	11	12
2	Same	12	120	7	6	6	0	6	2	6	5	1/3
3	Negative	69	92	6	3	6	2	5	2	7	5	3/3
4	Positive	76	65	1	1	7	1	5	2	6	5	2/3
5	Negative	29	64	0	2	0	0	7	0	4	5	1/3
6	Negative	27	68	4	3	6	0	5	1	6	5	0/3
7	Negative	26	159	2	4	4	-	5	5	5	5	2/3
8	Negative	24	72	5	4	7	2	4	4	7	5	3/3
9	Negative	58	119	5	1	7	1	5	2	7	5	3/3
10	Negative	13	65	1	0	0	0	5	0	3	5	1/3

1. Label predominance (negative, positive, neutral); 2. Frequency of emotion labels used; 3. Presence of physical symptoms; 4. How much thought about writing; 5. How much talked about writing*; 6. Positive effect; 7. Negative effect; 8. How happy felt over the past 4 weeks; 9. How sad felt over the past 4 weeks; 10. How meaningful/valuable has experience been; 11. Would they participate again 5 = 'definitely yes'; 12. Number of improved outcomes observed
1= 'not at all' to 7 'a great deal'

Seven of the nine participants used predominantly negative emotion labels. Of those reporting therapeutic benefit on all three outcomes, all used a predominance of negative emotions. Two of the participants used a reasonably high number of labels. Participant 3 used 69, and participant 9 used 58. However, participant 8 also showed improvements on outcomes yet she used just 24 labels. Similarly, participant 7 who showed improvements on 2 out of 3 outcomes used 26 labels. Participant 4 showed improvements on 2 of 4 outcomes; she used a predominance of positive labels and used 76 labels in total.

Other hypotheses

A factor discriminating these two groups is that those who used higher numbers of emotion labels met Weinberger's (1990) criteria to be classified as having a repressive coping style. Thus, a potential hypothesis may be that a lower number of emotion labels are required by non-repressors as compared with repressors.

There were two additional discriminating factors. First, in each of the cases showing therapeutic benefit, increased physical symptom scores were evident. Second, in those instances where therapeutic benefit was observed on 3/3 outcomes a higher score was reported for the extent to which participants found the intervention meaningful or valuable.

Spiritual wellbeing

Other data relevant to quality of life were not included in the general case study. To assess whether ratings concerning one's spiritual well-being were impacted on by the intervention, a comparison of pre and post measures was conducted. The results are presented in Table 29. Of the participants that showed therapeutic benefit on all 3 outcomes, 2 showed substantial increases on spiritual wellbeing scores. For instance, participant 3 showed an increase of 5 points, and participant 8 an increase of 8 points. The other participant (i.e. participant 9) had high levels of spiritual wellbeing at baseline and these were maintained post-intervention.

TABLE 29
Spiritual Wellbeing Scale

<i>Participant ID</i>	<i>Baseline</i>	<i>Post-intervention</i>
2	28	28
3	34	39
4	37	35
5	25	24
6	29	28
7	27	35
8	30	38
9	36	36
10	28	28

Positive and negative effects – a patient’s perspective

As a final step in this evaluation, participants were asked to provide responses concerning positive and negative effects of the intervention and to offer recommendations concerning the future direction of the research.

Examples of participants’ responses are shown in Table 30. These responses were recorded verbatim by the researcher. In terms of suggestions for future research, all participants decided to provide copies of their writing to a local cancer organisation for possible publication and/or sharing with other cancer patients and survivors.

TABLE 30
IBS Positive and Negative Effects: Participant's Comments

	<i>Positive effects</i>	<i>Negative effects</i>
2	More you talk the better. Good to know what supports are out there	-
3	Forces you to take a honest look at your feelings; gave me a sense of purpose and control; Good to talk to someone who cares	
4	Believe help someone else; quite cleansing	More negative when actually happening
5	Ideas scattered around and put in a filing cabinet; I didn't want to think about it	Won't influence me at all; maybe an opportunity for others
6	May take further action to see a professional; Sorting out – nice to talk to someone neutral	Brought emotions to forefront and not sure if that is bad or good
7	Encapsulates a lot of past events and puts them into a context	Brought attention to some relationship issues thought I had dealt with; brings up deep seated emotions that have been held down and not dealt with
8	Very good as my husband can read	
9	Validation; acknowledgement; a chance to get emotions out rather than having them bottled up; gives a position from where to move on; brings them to surface	Brings up negative sides but gives a chance to file away.
10	None really	

8.9 Discussion

8.9.1 Overview

The focus of this study was on identifying processes that may be linked with improved outcomes reported in written disclosure studies. A particular emphasis was placed on

assessing the role of emotion regulatory strategies (e.g., emotional expression and emotional inhibition). The results indicated that for 3 of 9 participants, improvements in all three outcome measures: Impact of Event Scale (IES; Weiss & Marmar, 1998), Functional Assessment of Chronic Illness Therapy, General (FACT-G; Cella, 1989), and the Depression, Anxiety and Stress Scales (DASS; Lovibond & Lovibond, 1995) were evident. In each of these cases therapeutic benefits appeared to be linked with increases in emotional approach coping and decreases in the tendency to inhibit emotion. In contrast, for six of the nine participants some deleterious impact was observed.

The most concerning observation was that for several of these participants an increase in IES symptoms was evident following participation in the intervention. This finding was observed despite changes in emotion regulatory strategy. Thus, for these participants, an increase in emotional approach coping and a decrease in emotional inhibition was not uniformly associated with improved outcomes. This finding was unexpected, although there appears to be a sound theoretical explanation for why this occurred. As will be discussed, in a large randomised controlled designed study - as is typically used to assess the impact of written disclosure studies - such findings may be overlooked leading to inappropriately supervised applications of the written disclosure methodology.

8.9.2 Background and Aims

Although outcomes such as distress and quality of life were included in this study, the major focus was on attempting to identify potential psychological or contextual factors associated with the therapeutic benefits observed in written disclosure studies. In this study, the focus with respect to psychological mechanisms was specifically on emotion regulatory strategies.

For contextual factors, the main focus was on the nature, type and frequency of emotions used during writing. This latter focus was consistent with Pennebaker and Chung's (2007) A to D Emotion theory. Within this theory, Pennebaker and Chung (2007) propose that the use of

emotion labels in writing may be associated with improved therapeutic outcomes. For example, they suggest that the use of a moderate number of verbal labels in writing is more likely to lead to improved coping. In contrast, few labels (i.e. under representation of the emotional experience) are likely to lead to incomplete emotional processing resulting in increased psychological distress.

Pennebaker (1997) suggests that the inhibition of emotion constitutes an active cognitive process requiring the allocation of cognitive resources. According to Pennebaker and Chung (2007) transformation of traumatic experiences into writing, via emotion labels, is hypothesised to lead to reduced cognitive load resulting in decreased distress. Materials were purposively developed to facilitate the use of emotion labels in writing. For instance, standardised instructions were amended to include an emphasis on emotion labelling and a chart based on Parrot's (2001) primary emotions was used. Participants wrote about their illness experience according to stages of the illness experience (diagnosis, treatment, awaiting results, and remission).

8.9.3 Overview of Results

Impact on distress and quality of life

In addition to the 3 participants showing improvements on all outcome measures, 2 participants showed improvements on 2 of 3 outcomes and 3 participants showed improvements on 1 of 3 outcomes. One participant showed no improvement. Overall, 7 of 9 participants showed improvements on DASS scores; 4 of 9 showed reductions in IES scores; and, 4 showed improvements on quality of life scores. Three participants showed decreases in quality of life. Four participants showed increases in IES scores. In 2 of these cases, very low IES scores were reported at study entry. In the other two cases, moderate levels of stress, as per Horowitz's (1982) criteria, were indicated at study entry.

Change in emotion regulatory strategy

Four participants showed improved scores on emotional approach coping total scores, and 7 showed decreases in the tendency to inhibit emotion. Not all participants showed changes in all scales with some participants increasing in the tendency to inhibit particular emotions. Some participants showed decreases in emotional expression yet these decreases were not always associated with deleterious outcomes. For instance, a participant who showed improvements on all 3 outcomes reduced in her tendency to use emotional expression. Furthermore, higher levels of emotional approach coping were not always associated with lower tendencies to inhibit emotion. For example, very high levels of emotional approach coping were accompanied by very high tendencies to inhibit emotion in the patient who died during the intervention. This patient also had elevated scores on the avoidance subscale of the IES and high levels of hyper-arousal.

8.9.4 Critical Therapeutic Ingredients

(i) Decrease in inhibition on all scales

In this study, a critical factor linked with improved therapeutic outcome appeared to involve a reduction in the tendency to inhibit *all* emotions as measured by the CES scale (i.e. anger, depression and anxiety). For instance, in each of the cases where improved outcomes were observed on all measures, decreases on all inhibition measures occurred. In contrast, in participants where 2 of 3 outcomes were improved increases in the tendency to inhibit one particular type of emotion was evident (e.g., anger, depression). Furthermore, participants who increased in avoidance symptoms showed increases in the tendency to inhibit anxiety.

(ii) Expression of anger

In the majority of cases, an increase in anger occurred in the first week of the intervention. This may have occurred due to the nature of the writing topic (i.e. Diagnosis). Although many participants showed increases in anger, those participants showing improved outcomes on all measures showed substantial increases in anger in the first weeks of the intervention. It

also appeared to be important to express other emotions such as anxiety and depression, although the role of these emotions was less obviously linked with improved outcomes. In one participant, a flattening out of anger scores over the rest of the intervention followed the increase in the expression of anger early in the intervention period. In this instance, the participant showed increased tendencies to inhibit anger.

(iii) Ability to regulate emotional states

Participants differed in the extent to which scores on the STPI scales fluctuated over the course of the intervention. Those with increased fluctuation appeared to have improved outcomes post intervention. Some participants showed virtually no fluctuation across the intervention. According to Pennebaker (1997) some transient increases in distress are a necessary component of the therapeutic process. Moreover, some participants reported very low levels of physical symptoms immediately following the writing sessions. Low levels indicated on this measure may be an early indicator that the intervention is unlikely to be effective.

Interestingly, of those individuals showing little fluctuation, and low levels of physical reactivity 2 out of 3³⁴ met criteria to be categorised as having a repressive coping style. Giese-Davis and Spiegel (2002) report that individuals with a flexible affect regulation system are more likely to report reduced distress following the experience of cancer (see Chapter 4). Participants showing the most benefit from the intervention showed large fluctuations in the expression of different emotions (i.e., anger, depression and anxiety) throughout the duration of the intervention. This could imply that individual differences in terms of the ability to regulate emotional states exist.

³⁴ The third participant's scores may have been inflated due to the inclusion of a 'shortness' of breath item. This participant had reduced lung function and severe shortness of breath.

8.9.5 Repressive coping style and interpreting study results

In Chapters 4 and 5, the concept of ‘repression’ was introduced. However, no particular relationships were directly observed between Weinberger’s Adjustment Inventory (WAI; Weinberger, 1990) and measures of inhibition, coping style or distress. Nevertheless, in this study data reported in Chapter 4 were used to establish which participants met the criteria to be classified as a repressor. According to Weinberger and Davidson (1994) individuals who score low on the distress subscale and high on the restraint subscale of Weinberger’s (1990) Adjustment Inventory can be classified as having a repressive coping style. Five of the participants in this study met these criteria.

At study entry, all five of these participants reported DASS scores lower than general population norms (i.e. Crawford & Henry, 2003) and 3 of the 5 participants reported higher quality of life than the general population without chronic illness (Brucker et al., 2005). Of these, 3 had moderate to high levels on the IES scales at study entry. Furthermore, of the 4 participants who showed increases in IES scores, 3 were classified as having a repressive coping style. The fourth, whilst not categorised as a repressor, had very low tendencies to use emotional approach coping. Of the 4 participants who showed decreases in quality of life, 3 were classified as repressors, and the fourth was low in emotional approach coping.

One participant who was classified as a repressor did show improvement on all three outcomes. Whilst the changes on the IES and the DASS were modest (low scores to begin with), significant improvement on the FACT-G was noted. This participant was experiencing her second diagnosis and had embarked on a variety of personal growth experiences. In other words, this participant appeared to be different from the other 4 participants as she had engaged in considerable exploration of her emotions prior to participating in the intervention.

Repressors – a defective emotion regulatory system?

Weinberger and Schwarz (1990) suggest that individual differences exist with respect to the personality/coping style known as being a ‘repressor’. Central to Weinberger’s (1990, 1997) account is that repressors have a defective emotion regulatory system (see Chapter 5). As noted, individuals who met Weinberger’s (1990) showed very little fluctuation in terms of their expression of emotional states during the intervention. They also showed the following characteristics: increased levels of avoidance at study entry, very low levels of distress, and inflated scores with respect to quality of life (i.e. higher scores than general populations).

Following the intervention, these individuals showed increases in avoidance, hyper-arousal and DASS scores and reductions in quality of life. These findings may be consistent with Giese-Davis and Spiegel’s (2001) proposal that repression is a particularly profound coping style that is resistant to intervention efforts. This finding may suggest that repressors are at particular risk of experiencing adverse effects following involvement in an intervention focused on the expression of emotion.

Alternatively, these findings may indicate that the intervention has resulted in participants acknowledging and confronting their distress. In other words, participants, via the process of confrontation, may be moving towards more effective and complete processing of their emotional experiences. This interpretation would be consistent with cognitive accounts that emphasise confrontation (Quartana et al. 2006). For instance, in Chapter 5, it was argued that the effectiveness of interventions focused on encouraging the expression of emotion may involve assessing for increases in distress, rather than decreases. For instance, it could be argued that those participants who showed very low levels of distress, and inflated levels of quality of life (relative to other populations) have shown beneficial outcomes following involvement in the writing intervention. For instance, their self-reported levels of distress are no longer underestimated.

Inhibition: An active conscious process

In this study, high levels of emotional approach coping were linked with increased reports of avoidance and hyper-arousal, and higher levels of emotional inhibition. This finding suggests that emotional inhibition is an active process requiring the expenditure of considerable emotional processing and thought. This view would be inconsistent with early Freudian theory, however, the finding would be consistent with cognitive accounts, particularly those involving confrontation (i.e. Quartana et al. 2006). Higher levels of emotional processing were not always linked with high levels of hyper-arousal or avoidance symptoms. In several participants who showed therapeutic benefit, higher levels of emotional approach coping were also evident, although arguably these participants tended to report higher levels of emotional approach coping at baseline.

Research Interview – Evidence of increased distress due to confrontation?

In Chapter 5, the results indicated that increased emotional processing and expression were linked with increased distress. A potential hypothesis for this finding was that participants were engaged in a process of confrontation during the research interview as many were disclosing aspects of their cancer experience for the first time. However, direct support for this hypothesis was not obtained. Levels of distress, as measured by the GHQ (Goldberg & Williams, 1988) generally decreased between the screening interview and research interview.

A dangerous mix: high levels of processing and inhibition

A potential indicator of maladaptive coping was indicated by the presence of high levels of inhibition when combined with high levels of emotional processing. This is consistent with results by Stanton et al. (2002) showing that males with higher scores on the emotional approach coping scales displayed an increased tendency to ruminate and report depression.

Optimal levels of processing

These findings do not imply emotional approach coping is maladaptive. Rather it appears that there may be optimal levels of emotional processing and that excessive emotional expression and/or processing – particularly when combined with effortful processing to avoid/inhibit emotional material - may be maladaptive. Future research combining the Courtauld Emotional Control Scale (CEC: Watson & Greer, 1983), the Emotional Approach Coping Scales (EAC; Stanton et al., 2000 and the Impact of Events Scale – Revised (IES; Weiss & Marmar, 1997) in a range of samples (cancer and healthy populations) may be able to assess these relationships further and provide reference data indicating optimal ranges in terms of emotional expression, processing and inhibition.

8.9.6 Contextual Factors

(i) Expression of negative emotions and increased arousal

This study identified several contextual factors that appeared to be linked with therapeutic benefit. Firstly, participants with improved outcomes used predominantly negative emotion labels, although one participant who showed improvement on 2 of 3 outcomes used more positive labels. Second, participants who had higher baseline levels in terms of spiritual wellbeing appeared to benefit most from the intervention. Other factors linked with improved outcomes included an increase in physical symptoms (e.g. heart racing, sweaty palms) immediately following writing.

(ii) Number of labels

It is difficult to know whether a low, moderate, or high use of labels is associated with therapeutic benefit. In this study, positive outcomes appeared to occur for patients who used more emotion labels, however, two participants who used fewer labels also showed benefits. A hypothesis was proposed that individuals with a pronounced tendency to inhibit emotion (i.e. repressive coping style) might benefit from using more labels. However, it may be that

the high use of labels in this study was associated with a total reconfiguration of the individual's emotional experience. Pennebaker and Chung (2007) suggest that the use of too many labels during writing, whilst not necessarily detrimental, may lead to a total reconfiguration of one's emotional experience.

(ii) Derivation of meaning – positive growth experience

Although criteria were not applied to assess the content of writing samples, the writing samples of participants who showed therapeutic benefit on all outcomes, appeared to contain examples reflective of intense exploration of emotional experiences. For instance, in addition to writing about the prescribed topics, these participants also wrote about how the experience of cancer had led to changes in their views of themselves and the world. These participants seemed to engage in a process whereby meaning was derived from the experience and issues of personal reflection and growth were focused upon. This observation was consistent with high ratings on a post evaluation measure that assessed the extent to which participants found the writing experience meaningful or valuable to them. Increases observed on the spiritual wellbeing scale were also consistent with this observation.

(iii) Fewer labels may be associated with repressive tendencies

Some participants used very few labels in their writing. According to Pennebaker and Chung (2007), these individuals are at risk of under representing their emotional experience. Consequently, these individuals may continue to experience distress due to incomplete processing of emotional material. In this study, 3 of the 4 participants who showed elevated levels on the IES scale used fewer labels than did other study participants. One participant who reported very low use of emotion labels showed substantial increases in both avoidance and intrusions. Two other participants showed increases in avoidance, whilst the fourth showed decreases in avoidance but increases in intrusions.

In these instances, the intervention may have initially led to a decreased tendency to inhibit unpleasant emotional experiences, for example, as shown by overall decreased tendencies to inhibit emotion. During the process, some individuals - perhaps those not having the ability to apply 'relevant' emotion labels - may have resorted to a previous dominant coping strategy. For instance, some individuals may not have a tendency to inhibit all emotion but rather they may have a dominant strategy that involves the inhibition of anger, or anxiety.

8.9.7 Methodological Approach

Previous research has shown that application of the written disclosure method is associated with improved outcomes (for reviews see Sloan & Marx, 2004a; Smyth, 1999). In many of the studies the major outcomes used to assess the efficacy of the approach have focused on physical health. Generally, this outcome has been operationalised as reduced numbers of physician visits. Few studies incorporate measures such as the IES, or emotion regulatory strategies (i.e., inhibition/expression). Furthermore, the preferred research design used to assess the efficacy of the written disclosure paradigm has involved application of the Randomised Controlled Trial (RCT).

Whilst this approach provides a robust indicator of the extent to which a particular therapeutic approach has been effective, it provides limited information concerning the processes involved. Westen, Novotny and Thompson-Brenner (2004) suggest that an overemphasis on the RCT as the gold standard in research has limited the development of knowledge concerning therapeutic processes and theory underpinning psychotherapeutic approaches.

Rather than focusing on treatment packages constructed in the laboratory designed to be transported to clinical practice and assuming that any single design (RCT) can answer all clinically meaningful questions, as a field we might do well to realign our goals, from trying to provide clinicians with step-by-step instructions for treating decontextualized symptoms or syndromes to offering them empirically tested

interventions and empirically supported theories of change that they can integrate into empirically informed treatments

Westen et al., 2004, p. 658.

8.9.8 Future Research and Limitations

In this study, the application of a case study design resulted in the generation of several hypotheses concerning potential processes and/or contextual factors that may be linked with improved outcomes in written disclosure studies. Importantly, this study also identified potential mechanisms linked with deleterious outcomes. The inclusion of the IES along with emotion regulatory measures (i.e. inhibition and expression) provided important information that may ultimately shed light on the mechanisms or processes associated with the written disclosure method. Multiple data collection points and the use of the STPI state scales also provided information regarding the nature of emotional expression across the intervention period.

Future research would benefit from assessing the long term effects of participation in emotion-focused approaches. For example, deleterious effects noted on the IES may resolve in the weeks that follow the intervention. The increases in symptoms on the IES and the changes in emotion regulatory strategies observed may be transient and part of the therapeutic process. A participant during the post-intervention evaluation noted that she felt that her participation in the intervention gave her a point from which to move forward.

Future research may benefit from incorporating theory relevant to posttraumatic growth and concepts such as resilience. For example, these constructs may also be important contextual factors and may impact on outcomes observed in studies involving written disclosure. In this study, gaining a sense of meaning and/or writing about positive growth experiences was evident in patients' qualitative responses. Similarly, increases in spiritual wellbeing were observed in some participants. Although the researcher did not set out to study the issue of

positive growth experiences, these were identified as potential moderator (i.e. contextual factors) involved in producing therapeutic outcomes.

Research investigating the concept of posttraumatic growth following the experience of a range of traumas has burgeoned in recent years (Park & Helgeson, 2006). Fewer studies have focused on reactions following illness but nonetheless some studies exist (e.g., Bower, Meyerowitz, Desmond, Bernaards, Rowland, & Ganz, 2005; Danoff-Burg & Revenson, 2005; Millam, 2004). A variety of terms are used to growth experiences including ‘benefit finding’, ‘posttraumatic growth’, ‘stress-related growth’ (Park & Helgeson, 2006), ‘thriving’, and ‘adversarial growth’ (Zoellner & Maercker, 2006).

Posttraumatic growth is typically conceptualised as having an impact on positive health outcomes; however, Park and Helgeson (2006) argue that ‘growth’ was originally conceptualised by Tedeschi and Calhoun (1995) as co-occurring with high levels of distress. This observation is consistent with Pennebaker’s (1997) proposal which argues that some form of distress is a necessary component of the therapeutic process in written disclosure interventions. Indeed, Park and Helgeson (2006) point out that a number of studies report inverse relationships with perceived growth and positive mental and health outcomes suggesting that perhaps higher levels of distress, at least initially, are linked with posttraumatic growth.

In a meta-analysis reported by Helgeson, Reynolds and Tomich (2006), posttraumatic growth was unrelated to quality of life, anxiety, distress, and physical health. However, posttraumatic growth predicted lower levels of depression and higher levels of positive affect. Importantly, particularly within the context of this study is that previous research links positive growth experiences with higher levels of intrusive thoughts (Helgeson, Reynolds & Tomich, 2006). In other words, posttraumatic growth may be linked with increased cognitive

activity, in this case intrusive thoughts. In the current study, some participants increased in IES scores, particularly on the intrusion subscale. Whilst the increase in IES scores could be viewed as a deleterious outcome, a plausible explanation exists. For example, on the basis of the research in the posttraumatic growth area, a plausible explanation is that participants were engaging in a posttraumatic growth experience. For example, they were thinking about the event, and were perhaps attempting to gain meaning, or perhaps benefit from their cancer experience.

As noted by Park and Helgeson, further research is required to determine the amount of growth that is associated with improved psychological adjustment. For example, research suggests that individuals who write about both benefits and costs following experiencing a traumatic event showed the most improvement, particularly on reports of psychosocial resources. In contrast, those participants who identified benefits only showed reduced psychological adjustment (Cheng, Wong & Tseng, 2006). Thus, when considering aspects of Pennebaker and Chung's (2007) A-to-D emotion theory such as the nature of emotions expressed (e.g., positive/negative) and/or the number of labels used in writing, it may be that the optimal strategy involves the use of equivalent amounts of positive and negative emotion labels.

Furthermore, the critical element in terms of the writing process is that cognitive processing is increased. Future research is required, however, to determine whether writing about positive or negative aspects of the event is most beneficial. Nevertheless, previous research within this area suggests that writing about the benefits of a trauma, versus writing about the traumatic event, resulted in more cognitive processing which in turn was associated with increased therapeutic outcome (McCullough, Root & Cohen, 2006).

Park and Helgeson note a range of conceptual issues that require further research. First, is the construct of posttraumatic growth unidimensional or multidimensional? For example, a variety of domains have been described including spirituality, positive changes in relationships and personal strength. Second, is the posttraumatic growth construct best measured as an outcome variable or is it better conceptualised as a process? For example, Zoellner and Maercker (2006, p.628) define post-traumatic growth "... as the experience of individuals who do not only recover from trauma, i.e. return back to pre-trauma functioning after a period of emotional distress, but use it as an opportunity for further individual development". On the basis of this study, it appears that posttraumatic growth may be better conceptualised as a 'process variable' with participants writing about positive growth experiences reporting improved psychological adjustment (i.e. reduced distress and improved quality of life).

Third, is the construct of posttraumatic growth an illusion? Park and Helgeson highlight the problems with self-report measures of posttraumatic growth and cite the research of Frazier and Kaler (2006) who reported that high levels of posttraumatic growth were linked with cognitive distortions. Other researchers concur with the view that the concept of post-traumatic growth is largely illusory, however, the Janus-face model of self-perceived growth incorporates a two factor model which specifies both an illusory component and a constructive component (see Maercker & Zoellner, 2004).

As described in Chapter 7, the concept of 'resilience' did not seem to be entirely applicable to this sample with at least 50% of participants meeting DSM-IV-TR criteria for a psychological disorder. Nevertheless, for the remaining 50%, the concept may have some relevance and may be an important consideration when applying interventions such as written disclosure. According to Bonanno and Mancini (2008), up to 50% of individuals react to traumatic incidents with resiliency. Bonanno (2004) defines resilience as "... the ability of adults in

otherwise normal circumstances who are exposed to an isolated and potentially highly disruptive event such as death of a close relation or a violent or life-threatening situation to maintain relatively stable, healthy levels of psychological and physical functioning, as well as the capacity for generative experiences and positive emotion.”

Moreover, Bonanno and Mancini (2008) identify four different outcome trajectories which are based on an individual’s reaction to trauma. These include: chronic dysfunction, recovery, resilience, and delayed reactions. Importantly, a number of factors can impact on these trajectories such as person-centred variables (e.g., coping strategies), demographic characteristics (e.g., gender, level of education), and sociocontextual factors (e.g. supportive relations and community resources). Although this research did not specifically include measures of resilience, future research may explore the role of resilience as a potential moderator variable on an individual’s tendency to use inhibition as a coping strategy. Consideration of delayed reactions in response to trauma may also be pertinent to this sample with some of the participants being some time removed from the initial trauma of having received their initial diagnosis of cancer.

In addition, further research may explore Weinberger and Schwarz ‘s (1994) typology approach that incorporates the following coping styles (reactive, sensitive, oversocialised, undersocialised, self-assured) in addition to the repressive style. Such an approach may facilitate knowledge concerning whether repressors do indeed have a defective emotion regulatory system, or whether they underreport levels of distress due to preserving a favourable social perception (Furnham, 1986). Using the typology approach, it may also be possible to assess the types of coping styles that are more likely to underestimate levels of distress in research settings (see Chapter 5). In terms of monitoring potential adverse outcomes, it appears that the use of the IES throughout the duration of the intervention may

be useful. This measure, unlike other stress measures, appears to be less impervious to ‘repressors’ tendencies to underreport distress.

The use of emotional labelling could be improved upon in subsequent interventions. In assessing the use of labels in those who appear to have shown incomplete processing (i.e., potentially those participants with increased IES symptoms), a lower use of labels may be a critical factor. Although not part of the research protocol, a participant circled the labels on the emotion chart and sometimes wrote these down or included them within her writing. In future applications of this methodology, it may be appropriate to have participants select the labels that apply to their experiences and then integrate them into their writing.

In this study some participants, particularly those with less formal education, found the writing process difficult. These participants used very few labels when writing. In a clinical application of this methodology, it may be useful to use the chart to guide disclosure via talking. Furthermore, for some participants shorter or longer intervention periods may be appropriate, although longer periods may lead to perseveration. For some participants a tendency to return to the same issues, irrespective of the writing topic, was observed. Future research could also include a measure relevant to capturing the extent of perseveration as it may be an unintended outcome of the intervention.

As noted, the use of a case-study design in this study was a particular strength of this study as it resulted in the generation of several hypotheses that may assist in working towards a more complete understanding of the role of inhibition and repression in coping. Though there are some limitations that apply to this study. Firstly, although the researcher attempted to apply the intervention in a structured manner, at times participants engaged with the researcher in considerable communication. Thus, some benefits noted may have occurred due to perceptions of support rather than the intervention process. Secondly, although the researcher

encouraged participants to use the emotion chart when writing, participants appeared to differ in the extent to which they used the chart. Thirdly, changes in outcome variables may have occurred independently of this intervention. Whilst two baseline scores were used to track changes in distress, only one baseline score was included for the quality of life measure. Thus, changes occurring between baseline and Time 1 (a 9 month time period) were not monitored. Therefore, it cannot be determined if changes in quality of life scores occurred as a result of the intervention. Furthermore, as described within the results section, other events occurred in patients' lives during the course of the intervention (e.g., actual or threatened diagnosis of recurrence), thus changes in distress from the commencement of the intervention (Time 1) to following the intervention (Time 4) cannot be directly attributed to participation in the written disclosure intervention.

8.9.9 Conclusion

Previous research involving the written disclosure paradigm encourages participants to write about their most traumatic experience. Participants in this study wrote about their experiences with cancer. Increases in emotional approach coping, accompanied by decreases in emotional inhibition were linked with improved outcomes. Individuals with a tendency to use a repressive coping style, and individuals with elevated IES symptoms appear to be at particular risk of adverse outcome following the implementation of a written disclosure intervention. Although, as noted, for individuals with a tendency to repress emotion, an increase – rather than a decrease – in distress may signal that the intervention has been effective. For example, as reviewed in Chapter 5, an increase in distress as opposed to a decrease in distress may be more relevant in interventions focused on encouraging the expression of emotion. As was discussed, this claim appears supported by theory relevant to the posttraumatic growth concept. Although claims concerning the impact of the intervention on distress and quality of life are limited due to the design of this study, future research should monitor the direction of changes on outcome variables – at an individual case level – to ensure that any adverse outcomes are noted.

9. A FOCUS ON PATIENT SATISFACTION AND EXPECTATIONS IN IBS PATIENTS

9.1.1 New Markers of Quality of Medical Services

In chapters 6 and 7 application of Glaser's (1992) grounded theory to data obtained in interviews with cancer patients revealed that understanding patients' expectations were particularly important when attempting to understand how patients evaluate the quality of health care. Talley and Spiller (2002) propose that understanding patients' expectations, particularly identifying any hidden fears patients may have are vital in improving satisfaction and reducing health care use in patients with Irritable Bowel Syndrome (IBS).

Within the chronic illness model framework, particularly as is emphasised in the approach adopted in the United Kingdom, an increasing focus on issues related to the quality of medical care is evident. For some conditions, outcomes such as 'survival' are less relevant and additional markers such as quality of life and patient satisfaction have been proposed as key parameters when assessing the effectiveness of medical interventions in the 21st century (Campbell, Hahn et al., 2001; Sutton & McLean, 2006). Arguably, the extent to which the construct of satisfaction is a valid outcome for assessing the effectiveness of medical care with respect to Irritable Bowel Syndrome (IBS) is unknown.

Whilst patients with IBS experience symptoms on a chronic basis, unlike other chronic illnesses, there is no single or accepted organic marker of IBS, and no known definitive treatment (Colwell, Prather, Phillips and Zinsmeister, 1998). In chronic illnesses such as asthma and diabetes a lack of treatment can be life threatening or lead to disease progression. In IBS, a failure to treat the symptoms is not life threatening, nor does it lead to the development of disease. Such a dilemma has led commentators to suggest that in IBS, significant resources are used unnecessarily (Camilleri & Williams, 2000). Yet as noted in Chapter 2, losses in productivity due to absenteeism (Dean et al. 2005), patients' reports of

impaired quality of life (Frank et al. 2002), coupled with escalating health care costs suggests that a focus on developing effective medical interventions is important.

9.1.2 Psychopathology and Increased Health Care Use

Research that focuses on evaluating the quality and effectiveness of medical interventions in IBS is limited. Instead, the majority of research in the area has focused on attributing health-care use to patient level factors such as high levels of psychopathology. Patients with IBS are described as frequent users of health services (Spiegel et al. 2005). Yet, it is estimated that only one third of individuals with symptoms seek medical treatment (van Dulmen, Fennis, Mokkink & Bleijenberg, 1998). In the United States and Europe, several studies compare characteristics of consulters versus non-consulters hypothesising that psychopathology is the main determinant (Creed, 1997; Herschbach, Henrich & von Rad, 1999; Ringstrom, Abrahamsson, Strid & Simmons, 2007).

This finding appears to be applicable to those participants who seek treatment from specialists, not general practitioners. Research suggests that in tertiary settings (i.e. outpatients, specialists) up to 50% of patients meet the diagnostic criteria for at least one psychological disorder (Creed & Guthrie, 1987). In contrast, in two large population-based studies (see Lydiard and Falsetti, 1999) equivalent rates of psychopathology were found between consulters and non-consulters in a primary care setting.

A complicating factor when assessing the validity of claims made concerning psychopathology and increased health care use is that conditions for which there is no known organic cause have traditionally been described as somatoform disorders. In other words, the condition is a psychological one. Adopting this understanding then all patients could be described as seeking treatment due to psychological causes. One must be cautious though in reaching such conclusions as there is some evidence of changing physiology in the gut in IBS patients (see Alaradi & Barkin, 2002).

Moreover, in many of the studies that claim that psychopathology is the main cause of health care use considerable variance in terms of predicting health care use remains unaccounted for. According to Herschbach et al. (1999) when investigating factors predicting increased health care use, the main contributors (accounting for the most variance on an outcome variable, physician visits) included the frequency of symptoms and depression. However, in this study approximately 60% of the variance on physician visits was unaccounted for.

Whilst IBS patients, particularly those who seek treatment in outpatient clinics, may have high levels of psychopathology it appears that other factors may also be important in terms of understanding why IBS patients are frequent users of health services. For example, research suggests that factors such as the severity of symptoms (Hillila, Siivola, Farkkila, 2007; Osterberg, Blomquist, Krakau, Weinryb, Asberg, Hultcrantz, 2000) or duration of symptoms (Talley, Boyce, Jones, 1997), may be better predictors, than psychological disorders such as depression and anxiety (Lee, Guthrie, Robinson, Kennedy, Tomenson, Rogers & Thompson, 2007). Some research also identifies other factors such as misconceptions patients have about their illness (Dancey et al. 1999); learned illness behaviour (Whitehead, Winget, Fedoravicious, Wooley & Blackwell, 1982); complaint related cognitions (van Dulmen et al, 1996); and/or attributional style (Crane & Martin, 2002).

Thus far, only a few studies have assessed the role that these factors play in terms of reducing health care visits. For example, van der Horst, van Dulmen, Schellevis, van Eijk, Fennis & Bleijenberg (1997) demonstrated that when general practitioners were taught to adhere to a set of best practice guidelines, particularly those emphasising a focus on patients' complaint related cognitions, patients reported a decreased need to continue to seek medical advice. Similarly, Bengtsson, Ulander, Borgdal, Christensson and Ohlsson (2005) showed that a program providing education to IBS patients (N=29) reduced subsequent health care visits.

9.1.3 A lack of focus on the effectiveness of medical interventions

The question concerning why patients with IBS are such frequent users of health services is not unique to IBS. Patients with other chronic illnesses are also described as frequent users of health services (Egede, 2007). Again, the proposal that psychopathology is the major determinant has been investigated, albeit inconclusively (Gurmankin, Maselko, Bauer, Richman and Kubzansky, 2007). For example, Gurmankin et al. (2007) suggest that higher levels of comorbid physical illness as opposed to psychopathology was the main determinant of health seeking in a sample comprised of patients with anxiety disorder.

In contrast to the research focus in IBS, in other chronic illnesses considerable research effort has focused on exploring mechanisms associated with improving the quality and effectiveness of medical interventions. In chronic illnesses such as cancer, diabetes, and rheumatoid arthritis, a focus on increasing patient satisfaction has been associated with better biomedical health outcomes (Walker, Ristvedt & Haughey, 2003); improved psychological adjustment (Butow, et al. 1996); and, adherence to treatment regimes (DiMatteo, 2003).

Talley and Spiller (2002) report on the results of several consensus reports concerning best practice approaches in reducing health care use in IBS patients. Specifically, they advocate for a treatment approach based on the principle of patient-focused care. Recommendations include: provide adequate information and support to the patient; assure patients that their symptoms are real; reduce the number of diagnostic tests, assess patients' expectations and hidden fears; provide an understandable explanation for the symptoms; avoid giving mixed messages (i.e. assuring patient then ordering extensive tests); refer to support groups if symptoms prove difficult to manage; assess for psychological disorders, or unresolved loss/trauma; and assess impact on, and availability of, psychological resources.

Other commentators also advocate for the development of effective doctor-patient communication (Talley & Spiller, 2002), and patient education (Benqtsson, Ulander, Borgdal, Christensson, & Ohlsson, 2005; Colwell et al., 1998; van der Horst et al., 1998).

9.1.4 Summary and Aims

Although best practice recommendations exist with respect to the effective management of IBS, to date these proposals have not been subjected to empirical validation. To date research has not attempted to assess the role of practitioner factors that may lead to dissatisfaction and prompt, for example, repeat consultations. Moreover, research has not attempted to capture the quality of the communication interaction between doctor and patient as appears was intended when the best practice recommendations were proposed by Talley and Spiller (2002). For example, central to Talley and Spiller's (2002) best practice recommendations is a focus on understanding the nature of patient expectations. Other commentators also suggest that unmet patient expectations lead to decreased levels of satisfaction with consultations (Brody, Miller, Lerman, Smith, Lazaro, Blum, 1989; Kravitz, Callahan, Antonius & Lewis, 1997; Kravitz, Cope, Bhrany & Leake, 1994).

The major aims of this study were to understand the nature of patient expectations at consultation and to identify any potential correlates of patient satisfaction/dissatisfaction. The focus of this study was on hypothesis generation, rather than confirmation of *priory* hypotheses. To facilitate such an inquiry, the methodology utilised was predominantly qualitative, patient focused, and based on grounded theory (e.g., Glaser, 1992)³⁵. However, to complement this analysis quantitative data with respect to measuring patient satisfaction, and other outcomes was included. This study aimed to:

³⁵ In this instance, the researcher judged that it was necessary to conduct a literature review prior to conducting the interviews. The purpose of the literature review was on identifying gaps in understanding and in developing a sense of where to begin with questions. As is described in the method section, consistent with the grounded theory approach, these questions were used to direct initial interviews, however, once data was obtained and constantly compared, new questions and hypotheses for investigation emerged.

1. Understand the nature of patients' expectations at consultation with a gastroenterologist;
2. Assess levels of patient satisfaction with a gastroenterological consultation;
3. Assess the extent patients perceive that their concerns were addressed during the consult;
4. Identify potential correlates/determinants of patient satisfaction/dissatisfaction;
5. Assess patients' understanding of an IBS diagnosis;
6. Assess patients' perceptions of the impact that living with IBS has on their daily living;
7. Identify potential factors linked with increased health care use; and
8. Assess the applicability of constructs such as patient satisfaction when evaluating the effectiveness of medical interventions.

9.2 Method

9.2.1 Participants and Sampling Method

Participants were recruited using a purposive sampling framework for maximum variation (Giacomini & Cook, 2000). For instance, in addition to meeting the diagnostic criteria for a diagnosis of IBS (as diagnosed by a senior consultant gastroenterologist), patients were selected on the basis of a range of criteria to ensure adequate representation of patients who seek consultation in an outpatient gastroenterology clinic. These criteria were reviewed in Chapter 1. All criteria were met with the exception of gender. Significantly more females (N = 17) than males (N = 4) attended the outpatient clinic during the data collection phase of this study. This is consistent, however, with the higher prevalence rate reported for females, particularly in samples presenting for treatment in outpatient clinics (Blanchard, 2003). Recruitment of participants continued until saturation was reached (Giacomini & Cook, 2000)³⁶.

³⁶ The point at which saturation is reached is debatable, particularly when applying grounded theory. In reality, when data are constantly compared and new hypotheses arise, data could continue to add new information. However, for the purposes of this study, saturation occurred when enough data relevant to generating a range of hypotheses relevant to the main areas of inquiry was obtained.

The sampling method adopted in this study resulted in a sample of 21 participants. They ranged in age from 19 to 71 yrs ($M = 44.23$, $SD = 15.18$). Data relevant to health behaviours and other medical characteristics were reported in Chapter 2.

9.2.2 Mixed Method Approach

Quantitative data

Quantitative assessments of patient satisfaction, perceptions concerning the extent to which patients' concerns were addressed, and perceptions concerning the impact of symptoms on daily living were recorded during the interview. Patients were asked: "To what extent were you satisfied with the consultation today?" Patients were verbally provided with a scale (e.g., 1 = 'not at all satisfied' to 7 = 'completely satisfied') on which to anchor their responses. Patients' perceptions of the extent to which their concerns were addressed during the consultation were measured on a scale of 1 = 'not at all addressed' to 4 = 'all concerns addressed'. Patients' perceptions of the impact their symptoms have on their daily living were measured on a scale of 1 = 'no impact at all' to 7 = 'severe impact'.

During the course of the interview, additional quantitative data were collected to record patients' perceptions of the severity of their pain, the number of services accessed (e.g., general practitioners, gastroenterologists, other specialists), the types and number of tests previously performed, and the extent to which patients' accepted their IBS diagnosis. Other questions assessed the referral method (i.e. general practitioner, specialist), type of appointment (initial versus ongoing), the number of appointments with the current specialist, whether a follow up appointment was scheduled.

Qualitative data

Preliminary items reflective of the main areas of inquiry were developed by the researcher, two specialist gastroenterologists working in outpatient clinics, and a clinical/health psychologist. These questions focused on: i) the nature of patient expectations prior to

attending an appointment with a specialist; ii) the extent to which patients' concerns were addressed; iii) inquiring into, or identifying particular aspects of incongruity between patient expectations and information provided by their general practitioner; iv) patient satisfaction and/or dissatisfaction with their consultation and/or others consulted for their condition; v) the number and types of services accessed; vi) what most bothers patients' about their symptoms; vii) the impact the symptoms have on patients' lives and identification of the area of life (e.g. social, work, family) most affected; viii) recommendations concerning how their level of satisfaction could be improved; and, ix) understanding of an IBS diagnosis.

The quantitative and qualitative questions were designed to complement each other. For instance, following patients' anchoring their responses with respect to their satisfaction with the consultation, they were asked questions such as: "What were the best [or worst] aspects of today's appointment?; What could have been done to improve your level of satisfaction?; Was there anything in particular you were dissatisfied with?.

9.2.3 Procedure

Conduct of the interviews

Interviews were conducted in an outpatient clinic located within a major Australian public hospital immediately following a consultation with a senior consultant gastroenterologist.

Interviews ranged in duration from approximately 30 minutes to 1 hour. All interviews were recorded and as described below were transcribed periodically during the conduct of interviews.

Analysis of Transcripts and Coding of Data

To reduce potential researcher bias and to ensure that the data reflected the patient's experience, rather than the researchers, as each group of interviews was conducted (typically 2 or 3 at a time), data were transcribed, compared and contrasted for information rich responses and checked for emerging categories (i.e. codes). Some questions that did not elicit

information-rich responses (i.e. participants answered yes or no) were either deleted completely, or else amended in an attempt to facilitate discussion and information-rich responses. As new codes emerged, additional questions were added to the interview schedule to facilitate confirmation and elaboration. A copy of the final interview schedule is provided in Appendix K.

Glaser's (1992) approach was used to code the data. In the first stage of analysis, data were selectively coded and assessed for incidences relevant to understanding patient expectations and in identifying potential correlates of patient satisfaction. Thus data relevant to these concepts were selectively coded. However, the data were subjected to open coding with respect to identifying categories relevant to patients' experiences of illness and when identifying codes relevant to explaining 'why' IBS patients might use health services frequently.

Presentation of Results

On occasion, results relevant to qualitative data and quantitative data are presented simultaneously. In other words, patients' responses are triangulated to assess for discrepancies and/or confirmation.

Focus Group

All participants were invited to attend a focus group where the principal aim was to subject the coding of the data to confirmation and/or elaboration.

Recoding of services accessed

To permit the conduct of inferential statistics (see Post-hoc Analyses in the Results section), patients' qualitative responses with respect to the number and range of services accessed were coded to reflect the amount of services they had accessed. Table 31 describes the process of

coding the variable to reflect an ordinal scale whereby minimal services were coded as 1 and 2, with increasing access of services, coded as 3, 4 and 5.

TABLE 31
Coding of Services Accessed (N = 21)

<i>Coded Value</i>	<i>Coding of Services Accessed</i>	<i>N</i>
1	1 general practitioner plus 1 gastroenterologist	11
2	1 general practitioner plus gastroenterologist plus other specialist	3
3	Several general practitioners plus several gastroenterologists	2
4	1 or more general practitioners, plus gastroenterologist, plus several consults in emergency departments	2
5	Several general practitioners plus several gastroenterologists, plus several consults in emergency departments	3

9.3 Results

9.3.1 Participants, Diagnostic and Referral Information

All patients were diagnosed by a consultant gastroenterologist specialist as having a functional gastrointestinal disorder, with a primary diagnosis of Irritable Bowel Syndrome. Though three patients were also diagnosed with Dyspepsia, and three other patients reported receiving a diagnosis of diverticular disease on a previous occasion.

The majority of patients were referred by their general practitioner (n= 13); other gastroenterologist (n= 2), other specialist (n=2), or via a clinical trial (n=4). The majority of patients had met with one specialist (52.4%), 2 specialists (23.8%), 3 specialists (19 %) or 4 specialists (4.8%). Eleven patients were attending the consultation for the first time, 8 were at their second appointment while 2 were attending third or subsequent appointments. Thirteen patients were referred to the outpatient clinic via general practitioners, 2 by other

gastroenterologist specialists, 2 by other specialists whilst the remaining 4 were taking part in a trial at the participating hospital.

9.3.2 Descriptive Statistics

Patients reported moderate levels of pain, although there was wide variation in responses ($M = 4.52$, $SD = 2.5$). Patients reported that their symptoms had considerable impact on their daily living ($M = 5.61$, $SD = 1.42$).

As shown in Table 32, patients' ratings of satisfaction with the consultation were high ($M = 5.95$, $SD = 1.20$). Similarly, patients reported that most, or all of their concerns had been addressed ($M = 3.19$, $SD = .98$).

TABLE 32
Descriptive Statistics for Main Study Variables (N=21)

	<i>Mean</i>	<i>SD</i>	<i>Scale</i>	<i>Min/Max</i>
Satisfaction with Consultation	5.95	1.2	1 – not at all satisfied to 7 totally satisfied	2,7
Concerns Addressed	3.19	.98	1 no concerns – all concerns 4	1,4
Impact of symptoms on daily Living	5.61	1.43	No impact to severe impact	3,7
Severity of Pain	4.52	2.5	No pain to severe pain	1,7

Tests

During the interview participants described different types of tests they had performed by various medical professionals (i.e. general practitioners and specialists). Typically, they were often unable to provide a definitive number with respect to the number of tests that had been performed. Qualitative responses with respect to the range of tests performed were coded to

reflect the major types of tests they had performed. For example, tests performed ranged from preliminary blood tests through to invasive procedures such as colonoscopies and endoscopies. As shown in Table 33, some patients had several tests performed and were currently scheduled to have further tests. Some patients were also part of a clinical trial that involved a gastric emptying test; these are not shown in the table.

TABLE 33
Tests performed as a Result of IBS Symptoms (N=21)

<i>Type of Test</i>	<i>Number of Patients</i>	<i>Percentage</i>
Blood only	3	14.3
X-ray/scan	1	4.8
Colonoscopy/Endoscopy	8	38.1
Several of the above	2	9.5
Most of the above	7	33.3

Services accessed

There was wide variation in terms of medical services sought. As shown in Table 34, approximately half of the participants had seen just one general practitioner and one specialist whilst the remaining half varied in that some had seen several general practitioners, several gastroenterologists, or other specialists (e.g., gynaecologist, gall bladder specialist), and some patients also reported frequenting emergency departments on a regular basis. Two patients, who both appeared highly anxious with respect to their pain, also frequented emergency departments. One of these patients, who also reported having a diagnosis of chronic fatigue syndrome reported regularly attending emergency departments as he reported that he would receive ‘*one on one attention*’ and would have a range of tests performed.

Another patient had been through the testing process on six occasions with 6 different general practitioners and 6 different specialists. According to this patient, each time she moved house

she would find a new general practitioner, report her symptoms, and begin the testing and referral process once again.

TABLE 34
Range of Services Accessed (N=21)

<i>Type of Service</i>	<i>N</i>	<i>Percentage</i>
1 general practitioner and 1 gastroenterologist	11	52.4
1 general practitioner, 1 gastroenterologist, and another specialist	3	14.3
Several general practitioners and several gastroenterologists	2	9.5
1 general practitioner, 1 gastroenterologist and frequently emergency	2	9.5
Several general practitioners, several gastroenterologists and frequently emergency	3	14.3

9.4 Results: Substantive Coding

9.4.1 Overview

As noted, all data were transcribed and coded according to Glaser's (1992) two step process, although there was less distinction (i.e. than as was reported in the cancer study) between the two stages. For example, in this study two substantive areas of inquiry were delineated at the outset of the study (i.e. patient satisfaction and expectations). Thus, the focus of the analysis was on identifying relationships among various categories such as identifying potential correlates of patient satisfaction, and on understanding the nature of patient expectations. Thus, in many instances, open and selective coding (i.e. identifying relations among categories) occurred in parallel rather than in two discrete stages.

Whilst the two main substantive areas of inquiry guided the analysis of data, it is important to note that data were also open-coded in an iterative fashion during the interview process and

again during analysis of the transcripts. During the interviews, as new categories emerged and if explicit questions were not included in the interview schedule, these were added. For example, early on in the interview process, patients discussed potential causes of their symptoms. Thus, an explicit question that asked patients what they thought caused their symptoms was added. Throughout the interview process these new categories were included in subsequent interview schedules and were subjected to confirmation and elaboration. During the analysis these responses were constantly compared and based on relevance and similarity and were then ordered into a higher order theoretical code: the development of the health care utilisation model.

Presented first are the results of the analysis with respect to patient satisfaction and expectations. Following this presentation, other categories emerging in this research are reviewed within a model of health care utilisation. The aim of this model is to provide a complete account of the data emerging from this study and to explain its relevance in terms of understanding health care use in IBS patients. As will be reviewed, patient expectations feature centrally in this model, although the role of patient satisfaction in this model is less clear and requires further research.

9.4.2 Patient Satisfaction

(i) Personal characteristics of the consultant (quality of communicative behaviours)

As noted, patients rate their levels of satisfaction with their consultation very highly. Thus, responses to questions such as how could their level of satisfaction be improved were not particularly rich. Nevertheless, when describing best aspects of the appointment, some data appeared relevant to understanding why patients rated satisfaction highly. For example, patients described personal characteristics of the consultant such as being a good communicator, giving good explanations, pleasant, a good listener, and being very interesting.

(ii) Perception that concerns addressed

Patients also identified that they were happy when they perceived that their concerns had been addressed. For example, a patient responded: “He listened to my concerns and addressed each one of them and addressed them in a way that I thought eventually something will happen” [Female: IBS Patient]. Indeed, evidence for the link between the extent one’s concerns were addressed and patient satisfaction were indicated when a correlation was performed entering extent concerns were addressed and patient satisfaction ($r = .70, p < .01$).

9.4.3 Potential correlates of dissatisfaction

Patients’ responses indicated a range of factors that may be important correlates of patient dissatisfaction.

(i) Disappointed that tests were normal

Generally patients expressed disappointment when test results were normal and tended to state that they were still experiencing symptoms: “All is clear but the pain or feeling is there ... he says everything clear but nobody knows” [Female: IBS]. In only one case was a patient satisfied with the reassurance of ‘normal tests’ indicating that she did not have a life-threatening condition. This appeared to be linked with a family history of cancer. One patient who had seen several specialists, including different kinds of specialists was convinced that the cause had not been found. She reported some solace in the fact that she had checked virtually every organ in her body. “I’m happy no problems because every part I check it” [Female: IBS]. Others were partially relieved when notified that their test results were normal, but many felt the need to state that their condition was real: “What’s going to happen next because I’m still having symptoms” [Female: IBS].

(ii) Uncertainty, continuance of symptoms – patients exiting services

Patients who were exiting services (i.e. no appointment booked) expressed dissatisfaction. The main issues appeared to involve uncertainty and a continuance of symptoms:

The thing is that the doctor doesn't know what is going on with me, so it left me with the same question, what is going on with me, what is wrong with me, there is nothing there but why am I feeling sick sometimes, why is my constipation there because it is not normal.

[Female: IBS]

A t-test was performed to assess whether those existing services were less satisfied than those who had an appointment booked. Whilst the mean score was lower for those existing services (Mean = 5.57, *SD* = .53) than those with an appointment (Mean = 6.00, *SD* = 1.6), the difference between mean scores was not significant ($t = .81, p = .51$).

(iii) Lack of understanding/acceptance of diagnosis

Interview questions were designed to assess patient's understanding of their diagnosis. But during the interview when patients were asked if they had received a diagnosis for their symptoms, either during this consultation, or at a previous consultation, only 7/21 of patients agreed that they had formally been given a diagnosis of IBS. Twelve of 21 believed they had never been given a diagnosis of IBS and a further 2/21 patients were unsure. This finding was particularly interesting because in all cases the referring gastroenterologist had stated the diagnosis explicitly to the interviewer in the presence of the interviewee.

It appeared the patients were focused on hearing the consultant inform them that their test results were 'all clear' and therefore they did not believe that they had been given a diagnosis. Examples of patient responses exemplify this lack of understanding and/or possibly a lack of acceptance of their diagnosis. When the patient was asked if they had received a diagnosis, the patient said: "No, he said everything is clear" [Male: IBS]. Another patient, after a significant delay in responding said: "Not a physical diagnosis ... Basically he said you are

clear” [Male: IBS]. Other patients also responded similarly: “No, he thinks I’m fine” [Female: IBS]; and, “He says that everything is clear, but nobody knows” [Female: IBS].

(iv) Physical explanation (even though not medically accurate) encourages acceptance?

In contrast, patients who had had been informed by a radiologist that they had an extra loop in their bowel, or extra long intestines were accepting of their diagnosis, were more willing to live with their condition, and were focused on symptom management as opposed to finding a cure. Explanations involving patients being told they had a sensitive stomach did not appear to have the same impact.

Satisfaction with other health providers

In terms of describing satisfaction with other practitioners, a common response was to state that they were still symptomatic and therefore concluded that they were not helpful. As one patient stated: “I’m still sick so I’d say they didn’t really help at all” [Female: IBS]. Others noted that general practitioners did not take their complaints seriously, or that other specialists tended to give them the impression that the symptoms were not real, or were imagined. Very few patients had sought advice from alternative therapists and typically those who had reported them to be unhelpful, as again, their symptoms were still present.

9.4.5 Patient Expectations

(i) Patient passivity

In exploring the types of expectations patients had with respect to their consultation, a range of questions were asked, commencing with: “What did you hope to get from your appointment today? But, it was apparent very early on in the interviews that either this question was not eliciting rich responses, and/or many patients found it difficult to articulate exactly what their expectations were when meeting with the consultant. For instance, a response from a participant included; “We came here not really with any expectations” [Female: IBS]. This inability of patients to articulate their expectations was consistent,

despite adding a range of prompt questions that attempted to assess this aspect directly from a number of perspectives³⁷.

(ii) Expect doctor-directed consultation

It appeared that many patients were quite passive in the role as patient and that they expected that the doctor would take the leading role during the consultation. Given this finding, which was obvious early on in the interview process, and given that some patients (later in the interview) tended to describe their expectations in terms of what they expected their doctor to do for them, the question was amended slightly. Instead of asking, “What did you hope to get from your specialist appointment today?”, the researcher asked, “What did you hope the doctor would *do* for you today?”

(iii) Understand ‘why’ – find a cause

Despite the initial difficulties noted with respect to gaining information-rich responses to the questions that explicitly sought to understand the nature and types of expectations patients had at consultation, patients identified a range of expectations with respect to their consultation with the gastroenterologist specialist. Some patients described multiple expectations; although, a common response from patients was that they wanted answers for *why* they were experiencing symptoms. Patients expected that a physical cause for their symptoms would be found and that a definitive treatment and/or cure would be provided.

(iv) Symptom management and improve quality of life

Some patients also expressed a desire to improve the management of their symptoms and/or their quality of life. Generally, categories were not independent. Patients tended to describe their expectations in the manner as exemplified in the following patient’s response:

³⁷ It is possible that some patients were attending their appointment on the basis of a recommendation from another specialist. In such situations, patients may not have thought a lot about what would happen at this appointment.

Manage it and be able to tell me why it came about basically. And ... what caused it and if there's a managing process or anything I can do to improve my quality of life

[Male: IBS]

(v) Guarantees and continuous care?

Although not a frequent response, one patient, even though her symptoms were currently under control appeared to want a guaranteed cure. She wanted a prescription for a medicine that would control her cramping symptoms (if they occurred again) for sure. Another patient simply expected that she would have another appointment booked!

(vi) Specialists expert knowledge/best options for treatment/ongoing treatment

Several patients expected that the consultant would have the knowledge, expertise, and experience to identify why their symptoms had come about. Other patients believed the specialist was in a position to provide the most definitive knowledge, and/or the best options for treatment and/ or the consultant could offer insight that had not been forthcoming in previous consultations. For instance, a patient who had seen multiple specialists responded: "I hope doctor [sic] can see a different side of the problem with me because I still feel pain in my tummy ... It's not my imagination" [Female: IBS].

9.4.6 Recommendations

Doctors have answers not patients

Patients were asked whether they had any particular recommendations they could offer concerning the management of IBS. Unfortunately, the researcher did not gain information rich data in this area. In fact, one patient expressed his surprise at the question, and said "*Doctors have answers not patients*" [Male: IBS]. Another patient suggested that one should keep changing specialists until a solution (or resolution of symptoms) is found.

Other, single, references were made to the following factors: more information on symptom management; maintaining a healthy diet; and not defining whole self as having IBS - "...see as just one part of being, not all" [Female: IBS].

9.5 Theoretical Coding: Development of the Health Care Utilisation Model

9.5.1. Expect to be Treated

In developing an understanding of what factors may lead to the development of patient expectations, other data contained in the transcripts provided some insight. For instance, when a patient was asked to offer recommendations concerning what could be done to help him manage his symptoms, he responded: "You mean after I've received treatment" [Male: IBS Patient]. Therefore, patients' expectations may not necessarily be framed with reference to a single consultation experience, but are probably best understood in terms of their general expectations concerning how the doctor will respond/manage and indeed 'treat' their illness.

In other words, assessment of a single consultation may not be sufficient to draw out information rich responses concerning a patient's expectations. Patients may not expect that a resolution will be reached immediately (i.e. at the particular consultation), and instead expect that over a given period of time (perhaps an unlimited amount of consultations) will eventually lead to a resolution of their symptoms.

9.5.2 Factors Increasing/Decreasing "Treatment Expectations"

Several codes relevant to identifying potential antecedent factors in increasing/decreasing a patient's expectations that they would be treated were identified.

(i) Beliefs about the role of doctors

Earlier, it was noted that patients appeared quite passive in the consultation process and they found it difficult to articulate what exactly what they wanted (i.e. expected) from their consultation. This ‘passiveness’ may be better explained by investigating a patient’s beliefs concerning the role that medicine, and more particularly doctors, play in our society. For instance, the majority of patients exhibited some surprise when asked if they sought medical advice when they initially experienced symptoms. As stated by one patient when asked if he sought medical treatment – “Yes, of course when I have a problem I go to the GP” [Male: IBS].

(ii) Doctors’ role to fix symptoms

Furthermore, there may be a belief that the responsibility for fixing symptoms is firmly placed with the doctor. For instance, a patient who had initially stated that she was not interested in a definitive diagnosis and instead expected the doctor to provide her advice on symptom management was disappointed when her doctor suggested that she needed to learn to live with her symptoms. The patient stated: “Live with it, I don’t want to live with it, my lifestyle says can’t live with it...Coming in to see you because I don’t want to live with it” [Female: IBS].

(iii) Testing, duration of symptom and participation in trials

Other factors appeared to increase patient expectations that a definitive cause for their condition would be found and/or that they would eventually be treated, resulting in either a complete resolution or significant decline in their symptoms. For those patients earlier in the process (i.e. awaiting a colonoscopy or endoscopy), the expectation that this procedure would “get to the bottom” of their condition was heightened. In contrast, patients who had lived with the symptoms for many years, and who had seen several specialists concerning their symptoms, were focused on symptom management and improving their quality of life.

However, there was still an element of hope that there might be a ‘magic pill’, as one patient described. For instance, when the researcher asked the patient to indicate the extent to which he was satisfied with his consultation, he responded: “I was satisfied to the extent of about 5 because you know there is always that little thing that there’s a magic table and there’s always that expectation” [Male: IBS].

Patients who were entering clinical trials had heightened expectations that a cause would be found. This aspect was emphasised more than actually being optimistic that the trial drug might actually reduce their symptoms. When commenting on his participation in an upcoming clinical trial, a patient made the following comments with reference to the consultant:

And, again [The Consultant] is trying to develop ways of analysing peoples’ symptoms versus actual physical symptoms to a mental state, basically finding out exactly what is going on. I’m showing the symptoms but haven’t got any of the diagnostics; the cause is not there, there doesn’t appear to be any inflammation. No, there is no reason for what I tend to be experiencing. If [The Consultant] can get to the bottom of it, or get closer to where [The Consultant] wants to be then [The Consultant] can head in that direction.

[Male: IBS]

(iv) Specialist behaviours

A range of specialist behaviours appear to have an impact on the patient’s acceptance of diagnosis and either increasing or decreasing expectations concerning the extent to which a definitive diagnosis would be reached and/or treatment provided. As reviewed previously, communication was often noted as extremely important and some patients commented that the doctor had given them a good explanation of their condition. Other patients appeared to need an opportunity to vent their concerns, and have someone listen to them; thus, the extent

to which the consultant 'actively listened' was important. Another factor that might influence return visits is the tendency of consultants to assure patients that they can come back if their symptoms get worse.

Patients returning to visit the consultant, for instance, did not return because their symptoms got worse, but rather because their symptoms had changed. It appeared that such a recommendation might lead to a patient becoming overly focused on their symptoms.

(v) Understanding of the diagnosis

Patients who had accepted or understood their diagnosis (i.e. agreed that the specialist had given them an IBS diagnosis) appeared to have lowered expectations in terms of finding the definitive cause of their condition. Thus instead of focusing on finding a definitive cause they were more concerned with management strategies in the hope that their quality of life could be improved. Patients who did not accept they had an IBS diagnosis appeared to link receiving a diagnosis with physical or organic causes, and were unwilling to accept (or did not understand) the functional explanation provided. Patients would often suggest that (The Consultant) had informed them that they just have a 'sensitive stomach'. To what extent this was linked with the consultants attempt to explain the functional nature of their diagnosis is unknown. As noted previously, patients who were informed by a radiologist that they had an extra loop in their bowel, or had particularly long intestines, seemed to be able to accept their diagnosis. In other words, it appears that when a physical link or cause is provided, patients may be more willing to accept their diagnosis.

(vi) Referral factors

Some patients reported dissatisfaction with the handling of their condition by their general practitioner and had come to believe that the general practitioner did not have the expertise to

advise them. This was often the case even when the general practitioner had conducted many tests and all results were normal. This belief is seen in the following patient response:

They stuck. Also I lost hope. Every time I go we'll do this test, we'll do that test. This and that. After 3 or 4 times, I think I was getting frustrated. She also getting frustrated, she couldn't find anything, she said I'll refer you.

[Male: IBS Patient]

And another patient said: "She knows when she is out of her depth or knows there are better facilities to enquire about what is going on" [Male: IBS Patient].

9.5.3 Increased Health Care Use: Other factors

A range of additional codes were identified. These codes reflect responses that were particularly pervasive in patients' accounts of their illness experiences and tended to evolve independently of any questions asked.

9.5.4 Psychosocial Factors

A range of psychosocial factors were implicated when patients were discussing aspects of their illness. For example, some patients acknowledged the influence of psychosocial factors potentially in the onset, exacerbation of their symptoms, and more generally in terms of their experience with living with IBS. These psychosocial factors are reviewed as follows.

(i) Stress

Stress was indicated as a factor that made symptoms worse, although patients did not necessarily link stress with the onset of their illness. Stress at work was linked with an exacerbation of symptoms in one patient, whilst another patient acknowledged that her symptoms had diminished following a change in life (i.e. returned from overseas). As

highlighted in the following extract from a transcript, a patient notes the role of loneliness in his experience of illness.

But I think the main thing is because I'm living alone. I believe if I'm living with somebody (I don't have partner) so if had [sic] a partner I believe everything be solved.

[Male: IBS]

(ii) Impact on daily living – social emphasis

Although specific questions were included in the interview schedule to assess patients' perceptions of the impact of their symptoms on their quality of life, this theme emerged when patients were asked: What is that most bothers you about your gut symptoms? Whilst some patients mentioned physical aspects of their condition (i.e. pain, diarrhea, wind), as shown below, many patients noted the impact their condition has on their social life.

Social life's down the tubes, people getting fed up with you, getting frustrated, disappointed, and that reflects on me because it's not the person I was before this and I was happy and since this its kind of hard to stay positive all the time and it gets you down a bit. It's hard, and plays a toll on my Mum as well, and my family, and friends, girlfriends...

[Male: IBS Patient]

In addition to impacting directly on patients' perceptions of their quality of life, patients noted feelings of stress associated with maintaining relationships, whilst others acknowledged the stress caused to others in their social network and family.

Physical versus psychosocial aspects?

Other patients noted physical aspects of their condition when they were asked what most bothers them about their symptoms. To assess the extent to which this particular sample was

most bothered by physical versus psychosocial aspects of their condition, responses were coded. Thirteen of the 21 patients referred to physical aspects of their condition such as: pain, uncomfortableness, bloating, wind, discomfort, not being able to eat a meal, weight loss, fatigue, wellbeing, sleep, concentration, lack of control regarding wind. Eight of the 21 identified psychosocial aspects that most bothered them about their symptoms such as: emotional, disabling, always monitoring food, wears you down, interferes with life, monitoring for toilets, careful about what eats, social and clothes – appearance (i.e. what clothes look like); lack of control, consistency.

9.5.3 Cognitive Factors

A range of factors relating to the way patients processed information, or thought about issues concerning their symptoms or illness were identified. References to issues of normalcy were common with patients often referring to their symptoms (e.g., diarrhea or constipation in particular) and making statements such as: “It’s just not normal”. Dysfunctional thoughts regarding the causes of their conditions were also noted. A variety of responses were noted. Some patients linked the onset of their illness with previous gastrointestinal infections, or food poisoning, others linked with gynaecological and/or liver, or gallbladder problems. As noted previously, several attributed directly to: “having a sensitive stomach”; “having longer than usual intestines”; or “having a loopy bowel”.

(i) Avoidance behaviours – hypervigilance, stress and anxiety

The avoidance of social situations was extremely common and the impact this had on their relationship with other members of their family was noted. From a patient’s perspective, issues of embarrassment due to wind and or a loss of control appeared to be linked with feelings of stress and anxiety. For instance, the tendency to avoid social situations and/or to be hyper-vigilant regarding the presence of toilets or types of foods eaten when out often presents problems not just for patients but for their entire family. In other words, IBS

appears not only to impact on the patient but also has an impact on their wider network of friends and family.

(ii) Erroneous conclusions regarding causes of symptoms

All patients appeared to have spent considerable time and effort into looking into what may be the cause of their symptoms. Patients showed a tendency to research (either via the Internet or other sources) possible causes of their gastrointestinal problems. Several patients described elaborate hypotheses and indeed had well formulated theories concerning what caused their symptoms. As follows, is presented an extract from a patients' extended response when asked what he thought causes his symptoms:

Ah one of the things that you know through my study and asked other people and all this. We have two orifices to the stomach, one which is beginning to the opening of the stomach (esophagus) and then one from the stomach to the duodenum. With the duodenum [sic] very affected by what you think. ... I mean this my analysis of things ... So it's all here, if I'm frustrated, or very angry, this will tighten up and the food will not flow, when the food not flow my appetite will also reduce and then getting weaker and weaker

[Male: IBS]

Whilst some of this patient's reporting contains elements of correctness in terms of physiology and the digestive process, the patient has become extremely focused (hyper-vigilant) about his symptoms and the causes of these. The patient also implicitly acknowledges the role of psychosocial factors (i.e. anger, frustration) in his experience of symptoms.

This tendency to search for causes of one's symptoms was a common finding across the patient sample, however, typically the associations were made with reference to food, although some also noted issues of stress. Others acknowledged that it could be a range of

things, and indicated that they monitored virtually every aspect of their living in terms of monitoring what things might trigger their symptoms. After being told that everything was clear following an endoscopy, a patient said:

This is just an indication to me that we [nb. Uses 'we' frequently as if in reference to him and his illness] didn't have any dysfunctional parts seen when they did the endoscopy. I'll go back and review what I'm eating and doing, and see how my sleep routine is and how I'm happy with work and communicating at work – I'll be consistent that way.

[Male: IBS]

(iii) Excessive Monitoring of Food/Eating Disorder symptoms?

Patients appear to be at risk of developing erroneous conclusions concerning the impact of some things they eat, or do, and the onset or worsening of symptoms. All patients noted monitoring their food intake, both in terms of quantity and types of food. In many instances this monitoring appeared obsessive with patients developing hypotheses, sometimes erroneous ones (e.g., avoidance of Vitamin C preparations containing ascorbic acid) regarding the causes that certain foods had on their bowels. Several patients had increased their fibre intake, avoided curries, spicy food, and take-away foods. Despite these efforts, most patients reported limited impact on their symptoms.

9.5.5 Psychopathology

High levels of anxiety also appear to be associated with going out, and some patients would certainly meet some of the diagnostic criteria for agoraphobia or social anxiety disorders. Furthermore, an overlap with some criteria relevant to a diagnosis of Anorexia Nervosa and Bulimia were observed with some patients reporting that they only eat a biscuit a day (or similarly small amounts of food). Another patient reported throwing up after a glass of water because she felt so bloated. The emphasis on body image is possibly an indicator that they might have untreated psychopathology that would be best addressed by referral to other

specialist services. One woman linked feelings of depression with her inability to wear the clothes she wanted to wear.

It is important to note that whilst specialist referral may be required to deal with particular psychological disorders such as Anorexia or Bulimia, factors relevant to psychological processes (i.e. the cognitive factors reviewed) do not necessarily require specific referral. In other words, patients - independent of having a DSM-IV diagnosis – appear to show the tendency towards over-monitoring of food, catastrophising the effects of certain foods on their symptoms; making incorrect attributions regarding the causes of their symptoms.

In women, in particular, a focus on their body's appearance, rather than the symptoms was noted. Several women were very concerned about the bloating, and the implications that had for what clothes they wore.

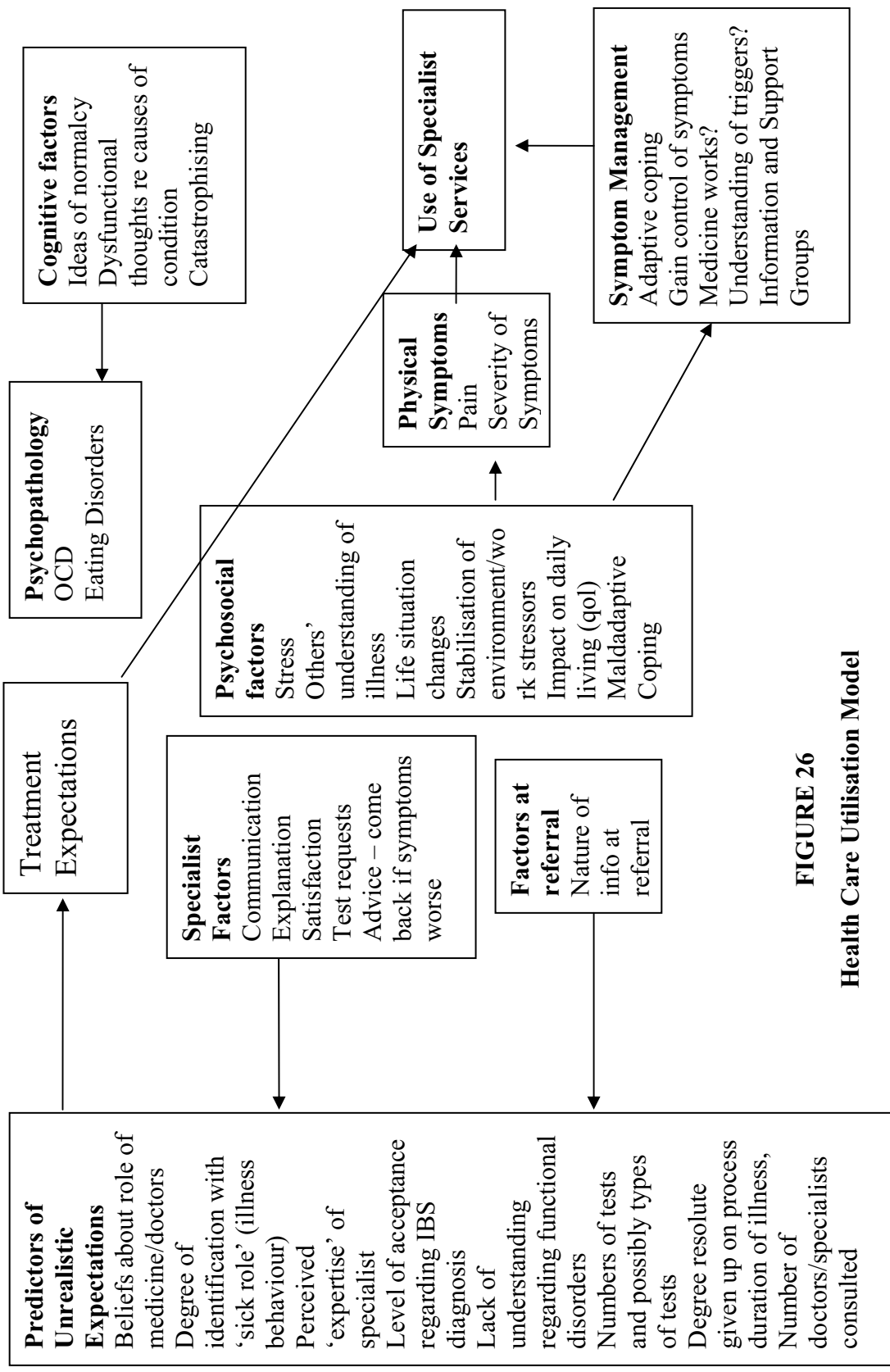


FIGURE 26
Health Care Utilisation Model

9.5.6 Health Care Utilisation Model

Shown in Figure 26 is a model that summarises the results presented. Central to this model is the construct of treatment expectations. For example, there appear to be many factors that may lead patients to develop expectations that their condition will be treated. These may involve patient level factors such as beliefs about the role of medicine, their acceptance/understanding of an IBS diagnosis. Similarly, specialist factors and factors at referral may increase patients' expectations that they will be treated. A lack of an appropriate explanation of IBS and the ordering of invasive tests may increase patients' expectations that a cause will be found and that they will ultimately receive treatment.

Also, there appear to be a range of psychosocial factors that may lead to maladaptive coping ultimately leading to increased perceptions of anxiety and stress which may exacerbate the patient's symptoms. Consistent with Drossman's (1998) conceptual model of IBS these factors may impact on whether or not a patient decides to seek medical treatment.

9.6 Post-Hoc Analyses: Inferential statistics

9.6.1 Predicting Services Accessed

As noted in the method section, data provided by participants during the interview with respect to the number and type of services accessed were coded on an ordinal scale to reflect the extent of services accessed. In particular, the researcher was interested to see if patients' evaluations of satisfaction with their current consultation were linked with the number of services accessed. The contribution of other study variables were also assessed.

Correlations among study variables

A complete table of correlations for all study variables is provided in Appendix L. As previously noted, patients' ratings of satisfaction at consultation were associated with their

perceptions that their concerns were addressed ($r = .70, p < .01$). Severity of pain was associated with services accessed ($r = .53, p < .05$) as was patient's perceptions of the impact their symptoms had on their daily living ($r = .62, p < .01$).

Multiple Regression: Factors Predicting Services Accessed

To test the contribution of each of these predictor variables on services accessed, a step-wise multiple regression was performed. Table 35 shows R^2 change for each step. The most important variables included severity of pain and patients' perceptions of the impact of their symptoms had on their daily living. The overall model accounted for 47% of the variance on services accessed.

TABLE 35
Predictors of Services Accessed

<i>Variable</i>	R^2	<i>Beta</i>
<i>Step 1: Severity of Pain</i>	.28*	.53*
<i>Step 2: Satisfaction with Appointment</i>	.01	-.10
<i>Step 3: Concerns Addressed</i>	.10	-.44
<i>Step 4: Impact on daily living</i>	.18*	.46*

Adjusted $R^2 = .47, F(1,16) = 5.51, p < .01$

Note ** $p < .05$

9.7 Focus Group

Consistent with the Participatory Action Research (PAR; Elden & Chisholm, 1994; Kemmis & McTaggart, 2005; Susman & Evered, 1978) approach adopted with the cancer research participants, all participants were invited to attend a focus group whereby the results of the research would be presented. Only 2 patients attended this session.

The session was attended by the researcher, a gastroenterologist and two participants and lasted for approximately two hours. The participants who attended the session had both left the formal system; however, both reported still experiencing symptoms. The researcher

presented the results in the form of a power-point presentation. This lasted approximately 40 minutes. It was the researcher's intention that the remainder of the time was to be spent discussing the relevance of the findings to the patients' experience. Furthermore, the researcher was interested in discussing the possibility of the participants being involved in an intervention focused on psychosocial aspects of the illness. However, with the presence of the gastroenterologist, the participants were mostly interested in finding out more about their condition and/or in complaining about the lack of information and support services available for IBS patients particularly as compared to other chronic illnesses (e.g., diabetes).

The gastroenterologist also spent considerable time attempting to understand why patients had difficulty in accepting their diagnosis. For instance, one patient present during the focus group would not accept that she had an IBS diagnosis. She believed that her symptoms were more severe than other people she knew who had an IBS diagnosis. The gastroenterologist was also focused on attempting to understand what patients expected of gastroenterologists. In this regard, patients supplied information relevant to the research objectives of this thesis (i.e. participation in health care). For instance, patients stated that they were unhappy with their gastroenterologist – and potentially the researcher although the participants did not state this – because they thought that questions concerning what they expected from their doctor were rude. In other words, they were of the view that it was the doctor's job to decide what to do.

Although an opportunity to validate the results was not forthcoming within this session, some major issues that are perhaps relevant to other patients exiting the formal system were identified. These included a lack of validation of the symptoms, particularly as compared with other chronic illnesses; a lack of written information regarding IBS (i.e. its causes and how to treat it) and, a lack of support groups.

The researcher did manage to get one question into the focus group. This involved an assessment of the willingness of participants to be involved in psychological intervention. Whilst the 2 patients were not against participation, both stated that they would only participate if there was a personal benefit for them. They both said that they were not interested in participating in research if it only helped others in the future. Given that a basic ethics requirement is that participants understand that there may not be any personal benefit to them, no further action was taken with respect to this study.

9.8 Discussion

9.8.1 Aims and Results

Best practice recommendations in IBS advocate for a patient focused approach that emphasises quality communication between doctor and patient and emphasises an understanding of patient expectations (Talley & Spiller, 2002). However, to-date, no known study has assessed these constructs using a patient focused approach. Adopting an exploratory and patient focused approach to interviews, the study aimed to understand the experience of patients living with IBS. A particular emphasis was placed on understanding the nature of patient expectations and on identifying potential correlates of patient satisfaction. Patients reported being most concerned with finding answers, and/or receiving an explanation for ‘why’ they were experiencing symptoms. Generally, patients expected that consultation with a gastroenterologist would result in the identification of a cause for their symptoms and that ultimately they would receive appropriate treatment.

In this sample, patients reported high levels of satisfaction with their consultation thus were disinclined to offer recommendations in terms of how the consultation could be improved. Nevertheless, when describing the best aspects of the consultation, typically patients described personal characteristics of the consultant and/or perceived that their concerns had been addressed. Patients who reached the ‘end of the road’ (i.e. they were not rebooked to see

the specialist) reported marginally lower levels of satisfaction and tended to perceive that less of their concerns were addressed. Uncertainty and a continuance of symptoms appeared to be the main concerns of these patients. Few patients formally acknowledged or accepted that they had a diagnosis of IBS; this appeared to occur because of patients hearing that all tests were clear (i.e. no known organic cause found).

9.8.2 Literature in IBS

A review of literature concerning IBS and health care use revealed a lack of research focus with respect to evaluating the effectiveness of medical interventions. Instead, the major hypothesis proposed is that IBS patients seek treatment initially, and on an ongoing and frequent basis largely because of high levels of psychopathology (Herschbach et al., 1999). In such accounts, there is an absence of acknowledgment of the role of doctors, the consultation process, or indeed other research that links psychological processes such as learned illness behaviour (Whitehead et al. 1992); complaint related cognitions (van Dulmen et al, 1996); and somatic attributions (Crane & Martin, 2003) with increased health care use. In contrast, a range of consensual reports, advocate for the adoption of patient focused and holistic approaches to the management of IBS (Talley & Spiller, 2002). In these approaches, the role of practitioners in reducing return visits is highlighted and a focus on factors amenable to change via specialist intervention is paramount.

9.8.3 Why do IBS patient seek frequent Health Care?

Central Role of Patient Expectations

In this study, patients' expectations appeared to play a central role in terms of understanding why patients continue to seek advice concerning their symptoms. For instance, as was shown in the Health Care Utilisation Model, patients' expectations were hypothesised to have a direct impact on health care use; however, as reviewed, there appear to be a number of factors that lead to the development of patient's treatment expectations. Although the initial focus of

interviews was on identifying and understanding the nature of patients' expectations, a range of additional, and pervasive, categories emerged in the analysis of patients' accounts of their illness experiences. Cognitive factors were particularly pervasive in patients' accounts. Elaborate theories and/or erroneous attributions regarding the causes of their symptoms were common. Similarly, a tendency towards hyper-vigilance of changes in symptoms and avoidance of foods and social situations were observed.

Severity of pain/duration of illness

Previous research suggests that factors such as the severity of pain (Osterberg et al., 2000) and/or the duration of illness (Talley et al., 1997) may be associated with a tendency to access health services more frequently. In this study, there were variations in perceptions of pain; however, overall patients reported moderate levels of pain. In a multiple regression analysis, patients' reports of the severity of their pain were linked with increased use of services. Yet, patients' perceptions of the impact of their symptoms on their daily living accounted for more variance on health care use. Patients' qualitative responses also emphasised the impact that their symptoms had on their daily living and they frequently noted issues of stress associated with its impact. States of anxiety and stress appeared to be associated with a patient's tendency to monitor the types of food consumed, the presence of toilets, and avoidance of social situations.

9.8.4 Quality framework

Applicability of satisfaction as an outcome of quality

The construct of 'patient satisfaction' was proposed as a possible mechanism that could be the focus of medical interventions and evaluations of its effectiveness. But levels of satisfaction failed to predict the level of services accessed in this study. The extent to which patient satisfaction can be used as a valid indicator of health care efficiency deserves further scrutiny. For instance, patients may be satisfied only for as long as the consultant is meeting their expectations (i.e. continuing to look for a cause and solution so that eventually a treatment can

be supplied). Thus, if practitioners aim to maintain high levels of satisfaction by meeting patients' expectations an inefficient model of health care would ensue. Some patients reported having the same tests performed repeatedly which undoubtedly leads to frustration at the doctor and patient levels, and results in considerable health care expenditure.

9.8.5 Developing effective strategies to improve the management of IBS

It appears that interventions likely to impact on reducing health care use in IBS patients will involve approaches directed at both the individual and health service delivery level. The results in this study support the proposal of Talley and Spiller (2002) that suggests that improving communication between doctor and patient is pivotal in attempting to reduce health care use in this group. For instance, at the practitioner level specifically targeting risk factors associated with return visits may involve a focus on patients' cognitions (i.e. what causes their symptoms – erroneous conclusions about physiology and certain foods) and unrealistic treatment expectations. Encouraging patients to accept their IBS diagnosis also appears to be an important determinant in the development of effective coping strategies. Referral for assistance to reduce levels of stress may also assist some patients.

(i) A focus on patients' unrealistic expectations

In their best practice recommendations for the treatment of IBS, Talley and Spiller (2002) emphasise the importance of understanding patients' expectations of the consultative process, particularly in terms of identifying any fears they may have. In this study, whilst patients reported anxiety with respect to the experience of their symptoms, the majority were not necessarily fearful. For example, in this sample only one patient was concerned that her symptoms might be linked with cancer. In this case, a family history of bowel cancer appeared to warrant such a fear. Overall, however, fear was not a factor linked with patient expectations in this study.

Other results indicated that asking patients what they hoped to get from their specialist appointment revealed few explicit expectations. These findings are consistent with previous research conducted with other samples. For example, Kravitz et al., (1997) suggest that patients identify fewer expectations when they are interviewed as compared with responding to a questionnaire. Perhaps patients are not necessarily cognisant of their expectations but are agreeable when prompted by items presented in a questionnaire.

Patient expectations are best described in terms of the consultation process (i.e. across the totality of the consultation process from first appointment to last appointment) and appear to be significantly influenced by patients' understanding concerning the role of doctors in our society (i.e. treating illness). More specifically, it appears that Rotter's (1954) social learning theory with its emphasis on 'expectations' is applicable in the context of this study.

... expectancies are the result of reinforcements, which act to either increase or decrease the expectancy that a particular behavior will lead to further reinforcements... Therefore, expectancies for a given situation are a function of the reinforcement history in that situation and a generalization of expectancies from other related behavior-reinforcement sequences

Carton & Nowicki, 1994, p. 32.

For instance, it may be important to consider a patient's prior reinforcement history with respect to their experiences with the health system. Such an enquiry may facilitate a discussion during consultation concerning the differences between acute and chronic illness. In the former, patients' expectancies that a cause for their symptoms will be found and a subsequent treatment applied are realistic. In contrast, with an illness such as IBS where there is no one accepted biological cause, or no known definitive treatment, holding such an expectation is unrealistic. It is important to note the implications of this interpretation. For

instance, given the nature of patients' expectations regarding the consultation process, once a patient reaches the end of the road there is a significant risk that they will continue to find an organic cause for their symptoms and will utilise further medical and specialist services.

Dealing with patients' unrealistic expectations by focusing on possibly discrepant aims or expectations of practitioner (testing to exclude organic disease) and patients (testing to find an organic cause) may prove beneficial in terms of establishing realistic treatment expectations. As was shown in the health care use model, antecedent factors such as patients' beliefs about the role of doctors/medicine appear to increase patients' expectations that they will be cured. Factors relevant to service delivery also appear to play a role in the development of patients' unrealistic expectations such as information provided by general practitioners, number and types of tests and entry into trials.

(ii) Improving explanations and understanding of an IBS diagnosis

Furthermore, it appears crucial to have a patient formally acknowledge their IBS diagnosis and understand the functional origins of their symptoms. Indeed, this explanation could be provided earlier in process (at the general practitioner level), and indeed referral to a gastroenterologist perhaps heightens patients' expectations that an organic cause for their symptoms will be found. Again, at the practitioner level, an explicit focus on the discrepant aims and/or expectations between patient (i.e. finding an organic cause) and practitioner (excluding an organic cause) may provide an opportunity to discuss patients' expectations openly. Further research that aims to develop a fuller understanding of factors involved in referral is required. For example, general practitioners may already provide an adequate explanation of IBS but patients may be particularly resistant to accepting a 'psychological' explanation for their illness.

(iii) Application of an integrative model of care

An example of an intervention that encourages patients to accept a psychological explanation for their symptoms is described by Gerson and Gerson (2005). They report on the success of an intervention delivered to a 35 year old woman with IBS. Using Drossman's (1998) model, a physician and a psychologist encouraged the patient to see the connection between her mental state ('mind') and her physical symptoms ("body") by using what they termed a "circle of effects".

On one side of the circle [they] noted how physical symptoms caused psychological distress, and then moving clockwise to the other side, illustrated how psychological experiences may have affected symptomatology.

Gerson & Gerson, 2005, p. 41.

During the course of the program, the therapist identified that the patient had unresolved issues concerning a trauma experienced. As a result, the therapist incorporated a writing intervention (vis-a-vis Pennebaker, 1997) which provided an opportunity for the patient to resolve her distress. According to the authors, over the course of the program the patient's symptoms did not decrease but the patient reported "that they seemed less upsetting to her [and] that she felt more hopeful about the future (Gerson & Gerson, 2005, p. 43).

(iv) Impediments to implementation: Expect application of biomedical model of illness

A major impediment to the successful implementation of an integrative model in the treatment of IBS is that patients may be unwilling to accept a psychological explanation for their illness. For example, patients appeared to expect application of the biomedical model in treating their illness. They perceived that an organic cause for their condition would be found and that ultimately they would receive treatment. Generally, patients expected that the specialist would take the leading role during the consultation process and some appeared to take offense at being encouraged to be active in the process (i.e. describing their expectations to the

consultant). This lack of active or consumer interest in managing their symptoms was further evidenced when only 2/21 showed interest in participating in a focus group.

(v) Improving access to information and resources

The Conservation of Resources Theory applied to the cancer patients in Chapter 7 may be applicable to understanding the psychosocial needs of IBS patients. For example, patients who attended the focus group noted an absence of resources in terms of information and support needs. Such information could also be incorporated and understood within Drossman's (1998) conceptual model of IBS. In Drossman's (1998) model, levels of coping resources are purported to mediate the effects of stress on IBS symptoms. For example, the provision of resources early in the process (i.e. when a patient first sees a general practitioner) may reduce distress and ultimately reduce the impact of the symptoms on the person's life.

9.8.6 Future Research and Limitations

Incorporating longitudinal designs

Future research would benefit from utilising a longitudinal design assessing for changes in satisfaction across the entire consultative process (rather than a single consultation). The moderating effects of potential correlates such as 'understanding/acceptance of IBS' would also need to be taken into account. Similarly, when attempting to assess the nature of patient expectations, it appears that questions with a more future oriented focus (e.g. Where do you hope to be with this condition in 12 months time?) may facilitate more direct responses with respect to patients' expectations.

Patients' beliefs concerning the role of doctors in treating illness may be a particular rich avenue for enquiry in future research and may provide further insight into patient acceptability of public policy recommendations such as SDM and multi-disciplinary approaches to treating IBS.

Limitations

Patients included in this study were recruited from outpatient services. Thus, the findings reviewed here may not necessarily apply to the general population of patients diagnosed with IBS. For instance, patients in this subset of the IBS population may be particularly assertive with respect to requesting referrals and tests. Similarly, these patients may be particularly resistant to receiving a psychological explanation for their illness. This may explain the low uptake to becoming involved in the focus group. For instance, all research participants were aware that the researcher was from the School of Psychology.

Furthermore, patients were interviewed at different time-points in the consultation process and some observations were made that concerned data collected from patients early in the consultation process versus those exiting services. Future research should interview patients several times and attempt to monitor changes in satisfaction and expectations.

Morover, the aims of the study were prefaced on the claim that IBS patients are frequent users of health services. In other words, this research was influenced by the literature that suggested that IBS patients are frequent users of health services. However, it appears that the conduct of this study was influenced by the quantity of citations stating this claim, as opposed to the quality of these claims. Whilst, many researchers suggest that patients with IBS are frequent users of health services, it is not clear to what extent IBS patients use health care services more than patients with other chronic illnesses.

Finally, the inferential statistics performed as post-hoc analyses may lack power due to the small sample and thus comments made concerning the utility of the 'satisfaction' construct may be unfounded. Nevertheless, the focus of this study was on hypothesis generation, and thus, the results have provided suggestions for areas that may be tested empirically using larger numbers of participants.

9.8.7 Conclusion

This study identified several potential correlates of patient satisfaction. Several of the findings may prove to have significant implications for the effective management of IBS. For instance, identifying and addressing patients' concerns and understanding patient expectations at consultation appear to be key determinants of patient satisfaction with care. However, the extent to which increasing patient satisfaction will ultimately reduce health care use is uncertain. This study identified an extensive array of factors potentially implicated in patients seeking specialist services. Thus, it appears that the direct effects model (i.e., psychopathology causes increased health care use) that has dominated the literature (see Hobbis et al. 2003) provides a simplistic explanation concerning why patients are frequent users of health services. Such an account will do little to improve efficiency in health care.

In summary, addressing patients' unrealistic expectations, encouraging patients to accept and understand their IBS diagnosis, and communicating realistic treatment goals might be an effective strategy to improve patient satisfaction. Ultimately, such an approach may result in reduced repeated consultations, testing and reduced health care use in patients.

Further research would seek to establish the extent to which the factors identified in this exploratory study contribute empirically to health care use in IBS patients.

10 DEVELOPING EFFECTIVE STRATEGIES TO IMPROVE THE MANAGEMENT OF CHRONIC ILLNESS

10.1 Development of Knowledge

The overall objective of this thesis was to work towards developing effective strategies to improve the management of chronic illness. The adoption of an approach that focused on disability and psychosocial aspects of the illness experience in two chronic illness groups, one with an organic origin (cancer) and one with no known organic cause (IBS), resulted in the generation of knowledge relevant to meeting this objective. As is summarised within this chapter, specific knowledge generated in this thesis resulted in the development of several proposals for individual and community level interventions. Each of which could potentially be used to decrease distress, improve quality of life and ultimately reduce disease burden occurring as a result of chronic illness. Similarly, proposals for improvements in the provision of information and the delivery of health services within the IBS sample were made. Implementation of such initiatives, combined with appropriate assessments of efficacy, may lead to significant reductions in health care expenditure.

Moreover, it is envisaged that the knowledge relevant to the intervention strategies proposed could be incorporated into public policy strategies aimed at reducing the impact of chronic illnesses such as cancer and IBS. For instance, it is anticipated that the knowledge generated in this thesis will form the basis of future and ongoing research agendas. In the long term, and with a focus on advocating for a holistic approach to health, which includes physical, psychological and social aspects of the illness experience, significant decreases in total disease burden and health-care expenditure could occur.

As was argued in Chapters 1 and 2, a focus on physical aspects of illness and an overemphasis on biomedical models of health, potentially underestimates burden occurring as a result of psychological distress. Furthermore, disease burden for chronic conditions for which no

known organic cause is known remains undocumented in Australia. With a focus on a broad range of psychological and psychosocial factors, literature was drawn from several disciplines (e.g., health policy, psychology, epidemiology, gastroenterology and psycho-oncology). The aim in drawing from diverse literatures was to integrate knowledge across disciplines potentially for use in developing strategies, and informing health policy, to improve the management of chronic illness. For example, it was argued in Chapter 1 that policy which aims to improve the management of chronic illness has focused on a limited number of issues (e.g., shared care, multi-disciplinary approaches to care). A lack of emphasis in health care models and public policy recommendations on individuals' reactions to their experience of illness led, in this thesis, to a series of studies focused on psychological and psychosocial aspects of the illness experience.

Thus, a range of psychological factors including distress, quality of life and individual coping strategies (e.g., emotional inhibition, positive spirit) were included. In addition, other factors reflective of potential inter-relationships between individuals and their social environments (i.e., 'psychosocial factors') attempted to incorporate measures reflective of patients' interactions and engagement with the health system (e.g., patient satisfaction with care, expectations of care, doctor-patient communication, and health care use) and the social system (e.g., communication with family and friends, community support services).

When considering recommendations proposed within the public policy literature, results in this research suggest that a focus on individual level factors (e.g., patient willingness to engage in Shared Decision Making) and psychosocial factors (patient expectations of care) are important when developing – and implementing – strategies aimed at reducing the impact of chronic illness at both a personal level (e.g., quality of life, psychological distress), and potentially at the health system levels (i.e. disease burden, health care expenditure, evaluations of care). Patients' expectations concerning the model of health care they expect,

and the timing of the application of such models was another important finding in studies reported in this thesis (see Chapters 6 and 7). Furthermore, on the basis of findings reported in this thesis, it appears that efforts to promote the application of the biopsychosocial model of health may need to consider i) different types of chronic illness (life-threatening versus non life-threatening) ii) stage in the illness trajectory iii) patient acceptability. Although the biopsychosocial model appears to provide a particularly efficient model for managing conditions of a non-organic nature, the willingness of doctors to endorse such models coupled with the willingness of patients to accept such models would appear to require further research.

An intriguing finding in this study was that IBS patients reported significantly more disability (i.e. increased distress and reduced quality of life) than cancer patients in this sample. Whilst it could be argued that the cancer patients in this sample were not highly distressed, four observations make this conclusion implausible. Firstly, cancer patients at interview were considerably distressed (overtly crying in the researcher's office). Secondly, half of the sample met criteria for a likely DSM-IV-TR diagnosis for a mood disorder. Thirdly, many patients' levels of distress reported at the commencement of this study were significantly below population norms for chronic illness groups and were significantly lower than healthy populations. Fourthly, levels of disability reported by the IBS patients were significantly worse than other chronic illness samples.

In attempting to explain the very low levels of disability (i.e. low levels of distress and high levels of quality of life) reported by the cancer patients, the researcher sought examination first from the wider stress literature and then the cancer coping literature. Many of the participants in the cancer sample reported some symptoms of Post Traumatic Stress Disorder (PTSD), although most were in the low or moderate range. Nevertheless, knowledge developed in this thesis suggests that 'distress' in cancer samples is best measured using

measures of acute stress as opposed to measures of chronic stress. This finding may have important implications for subsequent studies designed to assess for levels of disability and or levels of distress before and after application of a therapeutic intervention.

As discussed in Chapters 4, 5 and 8, the concept of emotional inhibition, and other related concepts (e.g., suppression, repression, fighting spirit) were critiqued. The incorporation of a conceptual and methodological critique of constructs which supposedly measure how individuals adjust to and cope with a cancer diagnosis (e.g., emotional inhibition, repression, suppression, fighting spirit) added depth to the work developed in this thesis. For example, several observations were made concerning how theory relevant to emotion regulation and coping could be developed. This critique also identified several ways in which measurement of these constructs may be improved. As described later in this chapter, concepts involving inhibition may be better operationalised in contemporary cognitive theory as opposed to Freudian theory. Similarly, approaches incorporating self-regulatory theory (see Diamond and Aspinwall, 2003), and in particular Stanton et al.'s (2002) emotional approach coping theory offer potential to develop a richer understanding of the adaptive (rather than maladaptive) function of emotional approach coping strategies.

In Chapter 8, the adoption of a case-study design when implementing the written disclosure method generated several hypotheses concerning 'why' and 'when' the therapeutic approach may be beneficial to cancer patients. The expression of anger in early stages of the intervention appears to a crucial factor associated with participants' engagement with the intervention process. Within the application of the written disclosure method further information was gathered concerning the potential problems researchers may encounter when assessing the effectiveness of written disclosure interventions. For example, outcomes that focus on decreasing distress may be at odds with the therapeutic approach because according

to Pennebaker (1997) an increase in distress is an important therapeutic component of the written disclosure intervention.

Although measures of posttraumatic growth were not included in this research, inclusion of research relevant to constructs such as resiliency and posttraumatic growth may add additional information concerning the therapeutic process associated with the written disclosure method. Importantly, theory relevant to posttraumatic growth suggests that the presence of posttraumatic growth when accompanied by distress and increased cognitive processing (e.g., in this study increased IES intrusion scores) may be a means by which a researcher can assess if the therapy is having the desired effect. As is discussed later in this chapter, it appears that engagement with the traumatic material, and active processing (not unconscious processing) is a critical theoretical component of the written disclosure process.

Incorporating Pennebaker and Chung's (2007) latest theory (i.e. the A-to-D Emotion theory) and specifically including the requirement that patients labeled their emotional experiences was a unique aspect of the study reported in Chapter 8. Indeed, to the Author's knowledge, this research represents the first application of Pennebaker and Chung's (2007) theory in a clinical sample. Knowledge developed from this study potentially contributes significantly to understanding why writing about traumatic experiences is therapeutic. The research identified potential moderators (e.g., repressive personality style) and other contextual factors (derivation of meaning, positive growth, increase in spiritual wellbeing, number of labels used) that may impact on the effectiveness of the intervention. Furthermore, and as is discussed in this chapter, important considerations with respect to emotion regulatory strategies (inhibition, suppression, repression) and whether they are conscious or non-conscious processes were highlighted. These findings would appear particularly important for researchers investigating the effectiveness of interventions focused on the expression of negative emotion.

Although limitations were noted with respect to ascribing differences between emotion regulatory strategies between chronic illness groups and healthy samples (see Chapter 5), a shift in the unit of analysis (social versus individual) resulted in new knowledge concerning the emotional inhibition construct. For example, the incorporation of Participatory Action Research (Susman & Evered, 1978), and Grounded Theory (Glaser, 1992) not only offered a unique insight into patients' experiences of living with chronic illness but it was evident that research constructs such as emotional inhibition and fighting spirit may be socially determined. This finding is contrary to previous commentary involving these constructs and offers a unique insight into how individuals attempt to cope and communicate with others concerning their cancer diagnosis. This finding may prove to be particularly important when attempting to encourage patients to seek available support from psychologists or community service organisations. As discussed later in this chapter, constructs such as 'fighting spirit' and particularly society's endorsement of such constructs may impact adversely on a patient's willingness to seek support.

Whilst research suggests that cancer patients generally decrease in distress over time (see Chapter 3), the precise time at which distress is no longer present is not known. Generally, research suggests that distress exists in long-term survivors and can be reliably measured up to 10 years post a cancer diagnosis (see Chapter 3). An important finding in the research reported in this thesis is that stress experienced may be more intense later in the illness trajectory than previously thought.

This information may be important when considering why individuals are reluctant to seek supportive care services during the initial stages of their cancer experience (i.e. diagnosis and treatment). As will be elaborated upon further in this chapter by incorporating Hobfoll's (2001; 1999; 1998) Conservation of Resources Theory (COR) into a community level

intervention, individuals with a tendency to inhibit emotion may be particularly at risk of developing high levels of psychological distress yet these individuals are less likely to seek support.

Incorporation of Hobfoll's (2001) COR theory was a key outcome in this study. As reviewed in Chapter 7, and when developing substantive theory, the COR theory provided an excellent account of the cancer coping process and explained contradictory findings with respect to patients seeking support. Despite the existence of a range of community services, participants reported a lack of uptake when first interviewed. However, when they attended a focus group several months later, patients had become proactive in seeking support.

Figure 27 summarises these key findings and integrates Hobfoll's COR theory with other key theoretical constructs described in this thesis (i.e. inhibition and positive spirit). In Chapters 6 and 7, it was suggested that Hobfoll's COR theory provides a complete account of the cancer coping process. Furthermore, it provides support for the notion that stress experienced by cancer patients may be more intense later in the illness experience, particularly when patients finish treatment and exit formal health services.

According to Hobfoll (2001; 1999; 1998) stress is experienced following the accumulation of losses. As shown in Figure 27, and across the illness trajectory, patients experience a range of losses. These were described in detail in Chapter 7. Commencing on the left hand side of the figure and following receiving a diagnosis of cancer, patients experience their first loss (i.e. threat to life). This is followed by another loss. For example, patients attempt to gain valued resources from individuals in their social network by expressing their emotions concerning their cancer diagnosis. However, others in their social network are not able to communicate (due to a lack of skill) or do not want to communicate about negative aspects of the cancer experience.

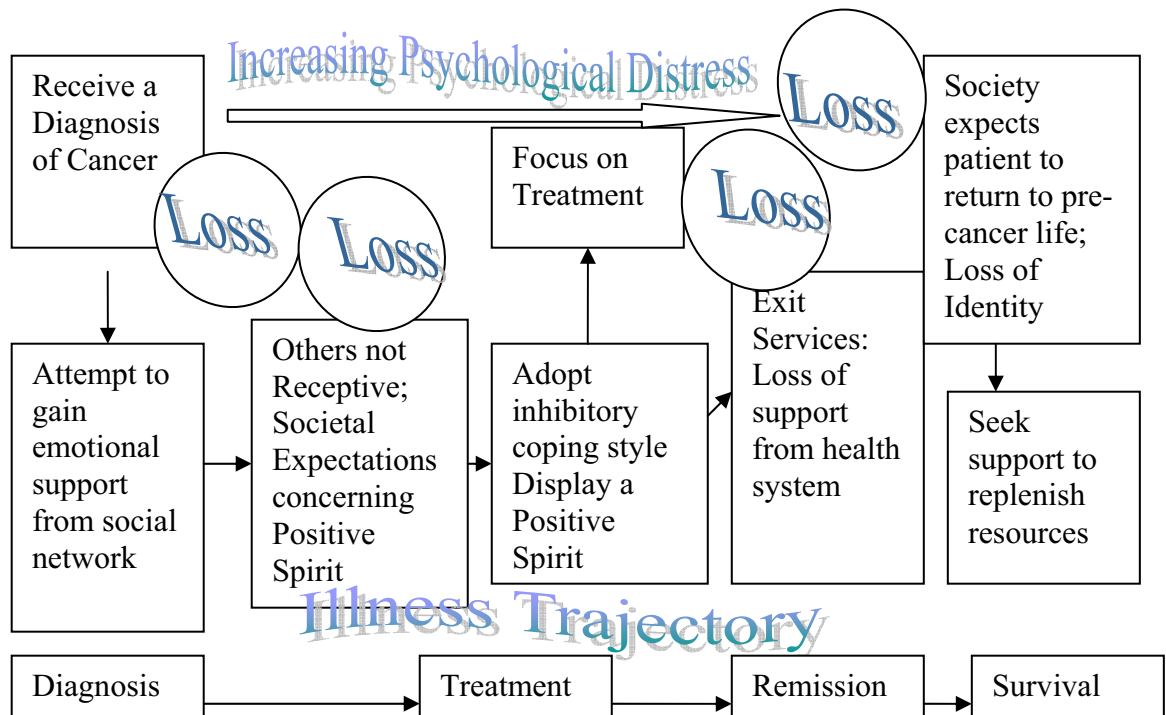


Figure 27. Incorporation of COR Theory and Research Results

As described in Chapter 7, society’s expectations concerning ‘positive’ spirit appear to underpin the belief that ‘positivity’ is the preferred coping strategy. Others’ reactions to patients’ attempts to express emotion and potentially gain valued resources appears to result in a change in a patient’s coping strategy. The patient then puts on a ‘brave face’ and will only communicate openly and honestly with others who have experienced cancer. At this time, patients appear to gather all remaining resources and focus on their treatment.

During the time of treatment patients experience an abundance of physical support from family and friends but when treatment is finished patients are expected to continue on with their pre-cancer life. At this point, and as depicted on the right hand side of the Figure 27, the patient experiences additional losses such as a loss of support from medical professionals and a loss of support from family and friends. Also as detailed in Chapter 7, when patients attempt to come to terms with the limitations imposed by the fatigue associated with treatment other losses become evident. Issues of identity and personal worth in terms of contributing to

family activities and society become an issue. As shown in Figure 27, it is at the point when patients are technically in remission that they might be more at risk of experiencing psychological distress.

At some time around remission, or for some participants several months after being in remission, several of the participants in this research decided to seek out resources (e.g. social and community supports). Although it is pleasing to see that some patients do eventually seek support, it is likely that many never do, or that others would have benefited from the provision of support considerably earlier in the process. Individuals who maintain a tendency to inhibit their emotion, and do not acknowledge any distress experienced as a result of receiving a cancer diagnosis, may be at particular risk of experiencing a delayed stress reaction, particularly in terms of the trajectory proposed by Bonanno and Mancini (2008) (see Chapter 8). A strategy which involves attempting to encourage early referral to support agencies, particularly for individuals low in resources is described later in this chapter.

Although not specifically assessed in the research presented in this thesis, it may be that there are individual differences that distinguish those who proactively seek support. For example, certain individuals may be looking for positive growth experiences or may be trying to make sense of their cancer experience. As noted in Chapter 8, future research that combines research on spirituality, resilience and positive traumatic growth experiences may add depth to understanding the role of emotion and self-regulation following the diagnosis and experience of cancer. The incorporation of this theory may be particularly important when informing the needs and supports required by cancer patients across the illness trajectory.

10.2 Summary of Research Findings

In this final chapter, the results of the research reported are reviewed in an integrated manner incorporating findings from quantitative (i.e., survey) data, qualitative (i.e., interview) data,

and the case studies (i.e. the written disclosure intervention). Within this account, specific recommendations for intervention for each of the chronic illnesses studied are proposed, and/or elaborated upon from previous chapters, and suggestions for future research are described. Implications of the results are discussed with reference to public policy recommendations focused on improving the management of chronic illness.

10.3 Strategies to Improve the Management of Chronic Illness

In Chapter 1 a review of the prevalence of chronic disease was provided. For instance, chronic disease now comprises a major cause of disease burden across the world. Chronic disease is not just a western phenomenon associated with increased wealth as once thought (WHO, 2005). Instead, chronic disease accounts for considerable disease burden in developed and under-developed regions throughout the world (Prince et al., 2007). Whilst considerable effort is focused on the prevention of chronic disease, organisations such as the WHO (2006) have suggested that additional efforts need to be directed at improving the management of chronic illness.

As reviewed in Chapter 1, the dominant model of health care is the biomedical model. In this model, the focus is on eradicating disease or infection. Due to the nature of illnesses predominant in the 21st century (chronic not acute), numerous commentators argue that the model is out of date and ineffective (Chew & Van Der Weyden; NSW Health, 2001; Walker et al., 2003). Advocates for change suggest that Engel's (1977) bio-psychosocial model is more relevant to the kinds of illnesses prevalent in the 21st century (Smith, 2008). Specific recommendations for improving the management of chronic illness focus on encouraging patient participation in health care (i.e. Shared Decision Making; SDM) and the adoption of a shared care model (i.e., implementation of multi-disciplinary teams).

As noted in Chapter 1, despite the provision of funding directed at improving the management of chronic illness and the existence of several programs directed at National Health Priority

Areas (NHPAs), to-date little empirical evidence is available as to whether these strategies impact on reducing health care expenditure or disease burden. In the United Kingdom, preliminary findings suggest that chronic disease models that encourage patient participation in care, and that adopt more holistic approaches to care incorporating multi-disciplinary approaches lead to improved patient outcomes such as improved self-monitoring behaviours and improved biological outcomes (reduced blood pressure) (Campbell et al. 2001; Sutton & McLean, 2006). Improved outcomes in terms of reduced health care expenditure, doctors' visits and less use of emergency services have also been reported (Bodenheimer et al. 2002, Campbell, et al. 2005; Feachem, et al., 2002).

In Australia, the major barrier in terms of assessing the effectiveness of programs is a lack of implementation of programs upon which assessments can be based. Harris and Zwar (2007) note that Australia is significantly behind other nations in terms of implementing strategies to improve the management of chronic illnesses. In Australia, impediments to implementation have focused on organisational aspects, in particular a lack of information and business systems, training in multidisciplinary teams, governance, and infrastructure (Proudfoot, et al. 2007). McCaffrey et al. (2007) suggest that a lack of an overall framework to guide policy is a major impediment in terms of implementing SDM in Australia. Others suggest that the number of different programs and complexity of initiatives coupled with a lack of integration contribute to a lack of uptake (Harris & Zwar, 2007; Hickie & McGorry, 2007; Proudfoot et al., 2007).

In general, the focus of identifying impediments to the uptake of programs – at least in Australia - has focused on organisational aspects and little, if any, consideration has been given to the impact of psychosocial factors on implementation. For example, the extent to which patients accept application of the key features of such programs (i.e. participation in care, bio-psychosocial model and shared care) remains unknown. Within this thesis, a focus

on the psychosocial aspects of the illness experience in two chronic illnesses, one of which is a National Health Priority Area (i.e., cancer), provided a unique perspective into identifying possible impediments at the patient level associated with the implementation of chronic disease models in Australia.

10.4 Shared Care: Multi-Disciplinary Approaches to Care

A central assumption upon which shared care models are proposed in the management of chronic illness is that they improve the efficiency with which services are delivered (NSW Health, 2001). Depending on the nature of the illness, patients may have a range of symptoms that require medical services across a range of specialties. Thus, rather than the patient seeking services independently, the care of the patient is coordinated via a team comprising doctors and health professionals with different knowledge and skills.

Existence of shared care models

Considering the data across both chronic illness groups, two patients made a direct reference to what appeared to be the existence of a shared care model of health. For example, one cancer patient noted that she contacted a breast care nurse. In South Australia, the provision of breast care nurses in hospitals is one initiative implemented on the basis of a shared care model. In this instance, the patient reported dissatisfaction with this service perceiving that inadequate support was received. For example, the communication she had with the breast care nurse focused on physical aspects of her condition and she reported feeling like a number. Another patient reported that she received additional counseling services which were facilitated on the basis of a program that existed in general practice.

Overall, however, cancer patients noted the lack of an integrative approach in the treatment of their illness. Patients noted a lack of attention to physical issues that were not the direct responsibility of the oncologist and those with complicated physical issues following the

acute phase of the illness, were responsible themselves for coordinating services with various health providers.

In IBS, there were no direct references made to the use of, or referral to, other health professionals who could assist patients in developing effective strategies to cope with their illness. Indeed, within the sample, it appeared that some of the patients may have met a DSM-IV-TR (APA, 2000) diagnosis for an eating disorder, yet no referral to a psychologist was evident.

Further research is required to assess patients' perceptions concerning the extent to which shared care models result in perceptions that they received integrated approaches to their treatment. Importantly, the provision of personnel within the shared care framework to provide emotional support appears to be necessary (Butow et al., 1996). The extent to which such models emphasise treatment according to a holistic model of care, incorporating both physical and emotional issues requires further research.

10.5 Participation in Decision Making

According to McCaffery et al. (2007), the concept of Shared Decision Making (SDM) is espoused in numerous policy and strategic documents, and tools to assist patients participate in decision making exist. Yet in a review of programs involving SDM in Australia, evidence of a wide gap between policy and recommendations and actual implementation was evident (McCaffery et al., 2007). Moreover, although many studies have been performed with respect to identifying barriers to the implementation of SDM, only 1 study was conducted in Australia (McCaffery et al., 2007). In the majority of studies reviewed internationally the focus is on identifying barriers at the health system and/or health practitioner level. Limited knowledge is available concerning patient level factors that may impact on the success of SDM initiatives.

Patient level impediments to the success of SDM initiatives

In the cancer sample, the majority of patients did not seek involvement in decision making concerning their treatment. They believed that the doctor, not the patient, had the specialised knowledge to decide what the appropriate treatment should be. In this case, the major impediment to implementation of SDM appears to involve patients' perceptions of their own competencies to make decisions concerning best approaches to treatment.

In the IBS sample, patients were encouraged to be involved in the decision making process. For example, patients were asked by their specialist, what they 'expected' the practitioner to do for them. As noted in Chapter 9, patients were not pleased with this approach. Again, patients believed that it was the doctor, and not the patient who should be responsible for deciding what to do. In other words, patients expected that the consultation would be based on a doctor-directed model of care rather than a patient-centred model.

The provision of SDM with the IBS patients was less than an ideal example of SDM. Nevertheless, there do appear to be patient level factors that will impede efforts aimed at encouraging patients to participate in their health care. For example, the PAR (Susman & Evered, 1978) approach was adopted throughout the conduct of the qualitative research performed in this thesis. Such an approach is consistent with health policy recommendations that encourage patient involvement in developing integrated and coordinated models of health care (NSW Health, 2001). In this instance, patients were encouraged to participate actively in the research process, by offering recommendations.

It was evident in the interviews that not all patients had the skills or personal confidence to offer recommendations. There were several instances where patients appeared stunned to be asked such questions. In these instances, patients seemed to think that such recommendations were the responsibility of the health care provider. Furthermore, not all patients appeared to

want involvement in research and/or in proposing ways in which the management of their condition could be improved. For example, the IBS patients were unwilling to be involved in the focus group, and the two who did attend stated that they were only interested in participating in further research if their involvement directly benefited them. In contrast, cancer patients were extremely keen to participate in any research as they wanted to assist others.

Implications of these results suggest that efforts to encourage patient participation in their care and/or management of their own condition will need to consider patients' abilities and willingness to engage in such processes. Considered together, the results in this study challenge policy recommendations concerning participation in decision making. Further research that focuses on patients' acceptability of such approaches is required.

10.6 Holistic Models of Care

As reviewed, the biomedical model of health has been criticised for its relevance when managing conditions most prevalent in the 21st century. A focus on symptoms alone, as opposed to considering the overall impact of the symptoms on an individuals' wellbeing is the major criticism directed at this model (NSW Health, 2001; Walker et al., 2003).

Furthermore, and as was argued in Chapter 2, current approaches to the measurement of disease burden underestimate the impact of chronic illnesses such as cancer and IBS. In IBS, despite its reported impact on health care expenditure (Jones et al. 2007), and reports of significant impairment in terms of reduced quality of life (Amouretti et al., 2006; Frank et al., 2002), data are not incorporated into reports of disease burden in Australia. In cancer, considerable epidemiological data exist but measures of disease burden tend to favour definitions of disability that emphasise losses in physical functioning and/or are limited in duration (i.e. during the acute phase of the illness).

Despite the criticism directed at the biomedical model, a complete and suitable alternative has not yet been implemented. Nevertheless, the adoption of a multi-disciplinary approach to the management of health is consistent with the bio-psychosocial model of health. However, the extent to which such approaches focus on emotional aspects as well as physical aspects, as is central to Engel's (1977) model, is not known. In IBS, the application of a multi-disciplinary approach in treating the emotional and physical aspects of the illness would appear to be the most effective way to manage such a condition. In a condition with no known organic cause, the application of a model that focuses on disease and identifying organic causes is likely to lead to increased health care use. Patients when searching for an organic cause for their condition are at risk of having the same tests performed on numerous occasions, and potentially with numerous specialists.

In contrast, in Drossman's (1998) model illness is defined in a manner consistent with the biopsychosocial model. That is, the model incorporates the role of psychological, biological and social factors in both the experience and treatment of the illness. Application of this model, with its focus on reducing stress and anxiety, may ultimately lead to decreases in the use of health services. Furthermore, adoption of Drossman's (1998) conceptual model may assist when providing an explanation of IBS. Thus, it is not clear why such an explanation is not utilised in practice. For example, whilst patients may be resistant to accept that their disorder has a psychological cause, it would be surprising if they would not acknowledge the role of stress in the development and/or exacerbation of their symptoms. The major barrier when explaining IBS as a psychological condition is that patients perceive that others do not believe that their symptoms are real (Talley & Spiller, 2002).

Drossman's (1998) model which provides a link between the central nervous (CNS) and autonomic nervous (ANS) systems may provide an explanation that is accepted on the basis of its psychological and physical connectivity (i.e. a mind-body explanation). For example, in

the interviews patients appeared more accepting of their diagnosis when the cause for their condition was associated with a physical abnormality (e.g., having extra long intestines, or an extra loopy bowel).

Patient acceptability of holistic/integrated models of care

In the IBS sample, patients expected the application of the biomedical model of health. That is, they expected that a consultation with a gastroenterologist would, on the basis of their symptoms and tests performed, identify the organic cause for their condition. Indeed, they were disappointed when no physical abnormality was found and could not understand why because they were still having symptoms.

In the cancer sample, patients expected application of a holistic model of care, however, they expected application of the biomedical model early in their illness experience. For example, patients focused on the competencies of the doctors in terms of treating their cancer and described their satisfaction with this aspect of care in terms of their survival. As described previously, patients shifted in terms of their expectations of the health care system later in their illness (i.e., following the acute phase of the illness). At this time, patients became focused on becoming well and appeared to define their health in broader terms than simply the absence of disease. Patients expressed some disappointment that a holistic approach was not provided by the health care system and several sought services with alternative therapists, apparently to fill this void.

Relevance of biopsychosocial model of care

In both illnesses studied, the bio-psychosocial model is highly relevant and applicable. Although the biomedical model is relevant to cancer in terms of managing the acute aspects relevant to eradicating the cancer, the bio-psychosocial model also addresses other physical and emotional aspects of the illness. As argued, application of the biomedical model of

disease to an illness with no-known organic origin will result in the increased use of health services. Furthermore, in a range of illnesses including those with medically unexplained symptoms (i.e. somatoform disorders), application of the bio-psychosocial model provides a conceptual basis upon which the development of symptoms can be explained and treatment approaches prescribed. With its emphasis on physical and emotional aspects of the illness experience, application of such a model may lead to improvements in the delivery of health services (i.e. multi-disciplinary teams) and may, ultimately, lead to reductions in health care expenditure and burden occurring as a result of such conditions.

Within Engel's (1977) bio-psychosocial model, health is conceived more broadly than simply the absence of disease, and thus is more compatible with the management of illnesses prevalent in the 21st century. For example, many chronic illnesses including several of those identified as NHPAs (e.g., diabetes, asthma, coronary heart disease) cannot be cured only managed. Although it is beyond the scope of this thesis to evaluate comprehensively the impediments associated with the implementation of bio-psychosocial models in the treatment of chronic illness, an attempt to identify some impediments is provided. Firstly, there appear to be many organisational impediments that potentially restrict the application of the model. For instance, the health system in Australia is principally designed to respond and deal with acute conditions. Secondly, a lack of uptake of chronic disease models appears to be linked with a lack of infrastructure and support at the practitioner level (Proudfoot et al., 2007). Thirdly, a lack of training in psychosocial aspects of illness may be a major impediment. For example, as compared with training programs that exist in Europe (Fritzche, Cierpka, Wirshching, 2003; Larisch, Schweickhardt, Wirsching & Fritzche, 2004), it appears that medical training in Australia may overly focus on biomedical accounts of illness.

Currently, it appears that specialists, particularly gastroenterologists, see their role in the treatment of IBS as one of principally conducting tests to exclude organic disorder. Whilst a diagnosis of IBS is based on exclusion, this does not appear to be an effective strategy to manage IBS, particularly when patients return to have the same tests performed with other specialists. Finally, there appear to be several – and perhaps overlooked – impediments at the patient level. In both chronic illnesses studied, patients expected application of the biomedical model in treating their illnesses. Indeed, for the cancer patients the application of the model is necessary for them to survive and issues of an emotional nature, whilst considered important, are viewed secondary to issues of survival.

10.7 A Focus on Disability and Psychosocial Aspects in Chronic Illness

As has been evident in this thesis, implementation of strategies to improve the management of chronic illness need to incorporate a broad approach to the issues that may ultimately impact on and/or inform the development of effective strategies to improve the management of chronic illness. Reviewed, as follows, are a range of factors that emerged from the conduct of research reported in this thesis. Specific recommendations and proposals for future research are also described.

(i) Measurement of Disability

As reviewed in Chapter 2, increasingly, quality of life measures are incorporated into studies aimed at assessing total disease burden, defined as incorporating the impact of disease, its treatment, and associated impacts on all domains of functioning (Mozaffari et al., 2007; Osaba, 1991). For instance, according to the WHO (1946), health comprises more than just the absence of disease, therefore, measures of disability should encompass disability experienced in physical, mental and social domains. In addition to physical, mental and social domains, several researchers emphasise the importance of including measures of spiritual wellbeing (Brady et al. 1999; Hiatt, 1985; Whitford, Olver & Peterson, 2008).

Using validated measures of quality of life (Functional Assessment of Chronic Illness Therapy; FACT-G, Cella, 1997) and distress (Depression, Anxiety & Stress Scales; DASS; Lovibond & Lovibond, 1995), data pertaining to the two chronic illness groups studied were compared with reference data (i.e. general populations and other chronic illnesses). Effect sizes were calculated and assessments of clinical significance were based on criteria specified by Webster, Cella and Yost (2003). Scores on the DASS were also compared in a similar manner with data from the two chronic illnesses studied compared with data from two general populations (Lovibond & Lovibond, 1995; Crawford & Henry, 2003) and one other chronic illness group (Nicholas et al. 2008).

Results indicated that the IBS group reported significant, and clinically meaningful, impairments on the quality of life measure when compared to means scores for the current cancer sample, general populations (with and without chronic illness) and other chronic illness groups. When assessing sub-domain scores of the FACT-G and DASS, results indicated that IBS patients reported lower scores (indicative of impairment) on the physical and emotional wellbeing scales. IBS patients reported higher levels of stress and anxiety but not depression when compared with the two general populations, although their levels of distress were comparable to the chronic pain group.

The cancer patients showed decrements in quality of life when compared to a general population (i.e. without chronic illness) though their scores were similar to a general population (with chronic illness). When assessing scores across a range of studies, cancer patients reported lower scores on the social and family well-being subscale of the Functional Assessment of Chronic Illness Therapy (FACT-G., Cella, 1997; Brucker et al. 2005). They reported lower than expected levels of distress as measured by the Depression, Anxiety and Stress Scales (DASS: Lovibond & Lovibond, 1995) (see Chapter 2).

(ii) Nature of distress experienced

When distress was conceptualised as involving acute stress (as opposed to chronic stress), the cancer patients reported similar levels of symptoms on the Impact of Event, revised scale (IES-R; Weiss & Marmar, 1997) subscales as individuals exposed to a range of traumatic events (see Chapter 3). Indeed, it appears that measures of stress, as opposed to general measures of emotion (e.g., depressed mood) appear to capture the nature of distress experienced by cancer patients. In Chapter 3, for example, measures of stress; that is, the hyper-arousal subscale of the IES-R (Weiss & Marmar, 1997) and the stress subscale of the DASS were superior when predicting quality of life, as compared to other measures of distress. Similarly, in the IBS group, measures of anxiety and stress, but not depression predicted quality of life scores. These findings are contrary to previous research that suggests that IBS patients predominantly suffer from depression and that this is the major cause of health care seeking (i.e. Herschbach et al., 1999).

The findings are consistent with Drossman's (1998) conceptual model of IBS. For example, Drossman (1998) emphasises the role of states such as anxiety and stress, but not depression, in the experience of symptoms. Furthermore, in Drossman's (1998) model a combination of factors, including perceptions of the impact that symptoms have on an individual's functioning, combine to predict health care use. As noted in Chapter 9, patients' perceptions of the impact of their symptoms on their daily living predicted increased use of medical services.

(iii) Recommendations for improving quality of life and reducing distress

On the basis of these findings, some recommendations are described. Other recommendations have been described within particular chapters presented in this thesis. IBS patients would benefit from the provision of support to improve their physical and emotional functioning and also to reduce anxiety and distress. Addressing those factors identified in the health care utilisation model such as maladaptive cognitions (e.g., erroneous conclusions, attributions

regarding the cause of their symptoms) and coping strategies (i.e. over-monitoring of foods, hyper-vigilance) may be an effective strategy to improve the management of IBS. Such a strategy may reduce levels of anxiety and stress and may ultimately reduce the intensity with which patients experience their symptoms leading to a decreased perceived need to seek medical services. For instance, central to Drossman's (1998) conceptual model of IBS is the hypothesis that impaired coping mediates the relationship between symptoms and health care use. Future research could assess the role of coping in patient perceptions of disability and health care use.

For cancer patients, it may be more useful to use the sub-domain scores of the FACT-G scale as decrements in these areas will direct or suggest areas where extra support may be required. Findings with respect to decrements in social and family functioning in the cancer group were consistent with previous research with cancer samples (i.e. Cella, Hahn et al., 2002). Furthermore, these reported decrements were consistent with comments made at interview (see Chapter 6). For example, participants reported difficulties in communicating with others in their social network concerning emotional aspects of their illness. Some noted an increasing distance in interpersonal relationships.

When developing effective strategies to improve quality of life, particularly in the social and family domain, it appears that education in helping patients and their families communicate would be of considerable benefit. As discussed in Chapter 7, societal expectations concerning expected ways of coping with cancer (e.g., positivity and fighting spirit) may have an adverse impact on interpersonal relationships. Educating family members regarding the increased burden that maintaining a positive spirit may have on the cancer patient could be a major component of such a program.

(iv) Emotional inhibition

In Chapters 4 and 5, the role of inhibition was considered as a possible mechanism to explain the lower than expected levels of distress reported by patients in Chapter 2. As reviewed, considerable debate exists concerning whether the concepts such as inhibition, suppression, denial and repression are related or distinct constructs (Garssen, 2007; Giese-Davis & Spiegel, 2001). Some preliminary evidence suggests that repression and suppression are separate constructs (Giese-Davis & Spiegel, 2001) but to-date no previous research has examined the extent of overlap among the range of measures used to assess inhibition.

Results reported in Chapters 4 and 5 indicated that little overlap exists among measures of inhibition. Similarly, their utility in predicting outcomes such as distress and quality of life was limited. In fact, results were contrary to theoretical proposals. Several conclusions were drawn and reviewed in detail in Chapter 5. The main issue appeared to involve the use of outdated theory and/or a lack of incorporation of relevant theory when discussing empirical findings. These criticisms of prior research and the lack of consistency between theory and empirical data have been reviewed recently (see Pauls, 2007).

A factor that appears to underpin inconsistencies reported in the literature, concerns whether the act of repression occurs at an unconscious or conscious level. Indeed, in Chapter 5, it was suggested that more knowledge may be gained by moving away from theoretical accounts that focus on unconscious processes towards more contemporary cognitive theories that consider the act of inhibition of negative emotion as requiring effortful processing (Erdelyi, 2001; Quartana et al. , 2006). Pennebaker (1997) suggests that active inhibition of emotion is a form of psychological work. Quartana et al (2006) suggests that effective processing of traumatic experiences requires deliberate and conscious processing involving confrontation with the emotional experience. Confrontation enables the individual to reinterpret the threatening aspects of the experience and consequently integrate aspects of the experience

with existing schema. This proposal is consistent with self-reports of patients who suggested that the written disclosure process enabled them to file away thoughts and/or provided them with a position from which they could move on from (see Chapter 8).

In Chapter 8, the main focus was on understanding the processes potentially responsible for therapeutic benefits of the written disclosure method, as are described in the literature (Sloan & Marx, 2004a; Smyth, 1999). In addition to looking at emotion regulatory factors (e.g. emotional inhibition and emotional approach coping), the role of contextual factors was explored. In particular, aspects of Pennebaker and Chung's (2007) recent A to D emotion theory were incorporated. Detailed results were reported in Chapter 8. Several important findings emerged with respect to proposing hypotheses concerning the role of inhibition and expression in coping. For example, factors associated with maladaptive coping appeared to involve high levels of inhibition when accompanied by high levels of emotional processing. This finding suggests, for example, that the act of inhibition may be an active and conscious cognitive process. Furthermore, individuals with a tendency to repress emotion appeared to have difficulties in regulating their emotions across the intervention. This finding provides support for Weinberger's (1990) hypothesis that 'repressors' have a defective emotion regulatory system. Information relevant to the construct of inhibition was also evident in the data obtained from interviews (see Chapters 6 and 7). For example, patients noted their tendency to shift their coping strategy to one of inhibition following initial attempts to cope using emotional expression. Others in patients' social networks were not receptive to this type of communication and the role of society's beliefs regarding positivity/fighting spirit in reinforcing this preferred coping strategy were noted. Whilst this finding would need replication in a larger and more representative population, it suggests that emotion regulatory constructs (inhibition/expression) might be state based rather than trait based.

For instance, Giese-Davis and Spiegel (2001) suggest that a major criticism of studies that investigate the role of inhibition is that they include only a single (i.e., one time) measure. In other words, it is not possible to determine whether these coping styles are trait based or state based. Perhaps a viable hypothesis is that measures of emotional inhibition are not necessarily measuring a stable coping /personality construct. Endorsement may be – at least in part- a function of a patient’s limited social support and/or a lack of receptiveness towards patients when they attempt to express emotion. As argued in Chapter 7, the data emerging from the interview study indicated that concepts such as inhibition and positive spirit might be socially determined, rather than personally determined. Further research is required to assess the differences between constructs of inhibition (i.e. emotional control as measured by the Courtauld Emotional Control Scale (Watson & Greer, 1983) and repression as is measured by Weinberger’s Adjustment Inventory (1990).

Based on the results reported in this thesis, it appears that the constructs are distinct and may have different determinants. Considerably more research is required to assess the extent to which these coping strategies exist in the general population. When comparing normative data on several regulatory measures, the extent of differences between cancer populations and healthy populations were not as robust as would be expected based on literature that links inhibition with the onset of disease (see Chapter 5).

(v) Communication

Aspects of communication were considered important in both samples though different emphases were evident. Similar characteristics were emphasised as ‘desired specialist’ characteristics. For instance, in the IBS sample, characteristics such as providing good explanations, being a good communicator, being pleasant, and a good listener were noted. In the cancer sample, specialist characteristics such as showing concern, sensitivity, kindness, empathy, being nice, encouragement, and understanding were emphasised. Yet, when these

characteristics were not present, patients tended to apply stereotypes, emphasise the doctor's professional competencies or blame the health system (e.g. lack of time and resources). Furthermore, cancer participants placed more emphasis on the importance of doctor-patient rapport. The extent to which the consultation experience was depersonalised appeared to be a major factor linked with perceptions of adequate rapport.

(vi) Patient expectations

Both samples were asked questions concerning their expectations. In the IBS group, the questions were directed towards the particular consultation they had with a specialist gastroenterologist, whereas cancer patients were asked a general question pertaining to their experiences with doctors. Responses specific to this question were not always information-rich. IBS patients expected that consultation with a specialist gastroenterologist would result in the identification of a cause for their condition and that an appropriate treatment would be provided. When cancer patients described their expectations they emphasised issues of survival and linked the absence of disease with the competencies of their doctors. However, patients also had expectations that they would receive holistic treatment incorporating physical and emotional needs, and that they would receive continued care.

It is important to note that in both groups the expectations appeared to differ according to the stage of illness experience. This finding may have implications for assessments (i.e. the development of questionnaires) involving patient satisfaction.

(vii) Patient satisfaction and evaluations of care received

In both groups, issues of patient satisfaction were explored. In the IBS group, quantitative assessments were complemented by interview questions aimed at identifying potential determinants of satisfaction. The results indicated that patients' ratings of satisfaction with their consultation with a gastroenterologist were high. Their ratings were associated with

their perceptions that their concerns were addressed. Patients exiting services (i.e., no follow up appointment was booked) tended to rate satisfaction marginally lower and perceived that less of their concerns had been addressed. Uncertainty and a continuance of symptoms appeared to be the main concerns of these patients. Lower levels of satisfaction were reported by patients whom had accessed more services. As discussed in detail in Chapter 9, possible determinants of dissatisfaction may involve a lack of acceptance and/or understanding of an IBS diagnosis and an expectation that the consultant would continue to search for an organic cause for their symptoms.

Questions concerning satisfaction in the cancer sample focused on understanding their satisfaction with treatment options. As reviewed in Chapter 6 and 7, patients reported that they did not receive treatment options. Although, they were not dissatisfied as they believed that they did not have the expertise to contribute to such decisions. Other findings with respect to patient satisfaction were more indirect and were drawn from other interview data. Specific hypotheses appear to warrant further investigation. For example, patient satisfaction with the health care they received during their experience with cancer appears to be multidimensional (i.e. refers to doctors and the health care system) and seems to change depending on the stage of their illness. For example, early in the treatment process (i.e. during the acute stage of their illness) judgements concerning satisfaction with health care are focused on doctors and on their competencies in curing their cancer.

Later in their illness (i.e., when their formal treatment has finished) patients are focused on becoming well. They emphasise the importance of a holistic approach to care incorporating physical and emotional aspects. In this instance, evaluations concerning the quality of care appear to be directed at the health system rather than individual doctors. Nevertheless, there was some dissatisfaction with doctors' management of the last appointment. Some patients appeared to expect acknowledgement of their role in the treatment process and efforts made

towards becoming well. For example, some reported dissatisfaction when medical professionals did not acknowledge their efforts at recovery, particularly if these efforts involved the use of alternative therapies.

As described in Chapter 7, further research that assesses the role of patient passivity during the consultative process and its impact on psychological adjustment is necessary. For example, previous research suggests that patients' expectations concerning involvement in treatment decisions are associated with psychological adjustment post the cancer experience (Butow et al. 1996).

In the IBS group, expectations and ratings of satisfaction also appear to be multi-dimensional, referring to the individual consultation, and more global evaluations (satisfaction with the management of their condition). For example, whilst patients rate their satisfaction with the individual consultant highly, this may be relevant to the stage of their illness, with those earlier in the testing process being satisfied whilst the consultant is continuing testing to find an organic cause for their condition. Again, these findings may be important in terms of developing measures aimed at evaluating the quality of care.

(viii) Support services

Specific questions were asked of cancer patients concerning their extent of uptake of available support services. Results from the research interview indicated a limited uptake of both community services and psychological services. Although not formally facilitated, patients reported valuing communicating with others who had cancer. In these situations they appeared to receive unconditional support and they could communicate openly and honestly. A reluctance to seek formal psychological services appears to be linked with perceptions that their distress was not serious enough, or that the professional would not have 'the cancer experience'. Factors associated with non-participation in community services involved

perceptions that services are for select groups (i.e., breast cancer patients), a lack of perceived need (e.g., were receiving support from family and friends), and a lack of knowledge/information concerning 'relevant' services. Participants generally had negative attitudes towards support groups perceiving that involvement might make them feel worse rather than better, although they said they would be more willing to participate later in their illness.

Consistent with Hobfoll's (2001; 1989; 1988) Conservation of Resources Theory (COR) it appears that earlier in the illness experience patients may conserve their resources. For example, they be reluctant to participate in support groups due to a fear that they may lose further resources. As described though in Chapter 7, several participants had become pro-active in seeking out available support services, including support groups, following participation in the research interview. In Chapter 7, the COR theory was used to explain participants' pro-active behaviour in seeking out valued resources.

In the IBS sample, no specific questions concerning support services were asked.

Nevertheless, the major complaints of patients who attended the focus group concerned a lack of information and support. Although these views could not be considered representative due to the very low participation rate in the focus group, other findings in this thesis suggest that information and support resources with respect to IBS are limited. A major issue identified involves a lack of acceptance and understanding of an IBS diagnosis. Indeed, patients do not appear to have been provided with adequate information or resources to assist them in understanding their diagnosis.

This factor, alone may contribute to maladaptive coping. For example, perceptions concerning a lack of support or information may lead individuals to access information from the Internet. Without the skills to assess the credibility of this information, patients may be at

risk of making erroneous conclusions and/or faulty attributions regarding the causes of their symptoms. This may lead to increased distress, reduced coping, and increased use of medical services.

10.8 Facilitating Access and Use of Support Services

(i) Educating Medical Professionals

As noted, in early stages of the illness experience patients appear to be reluctant to seek out support services, possibly due to a need to conserve all available resources. It is critical that early intervention is applied particularly for those individuals with limited resources. These individuals in an effort to conserve their limited resources may use coping strategies such as denial. As previously described, certain individuals (e.g., ‘repressors’) may tend to underestimate their levels of distress and/or overestimate their quality of life (see Chapter 8). Thus, medical professionals who suspect that patients have limited personal and/or social resources should directly encourage them to contact community service organisations irrespective of their self reports of distress.

Given the lack of referral evident in this study, it appears that increased education directed at health professionals is required. Encouraging medical professionals to be aware of the range of services from which their patients could benefit, and encouraging them to provide patients with a direct recommendation to contact the particular organisation would be a preferred strategy. However, in the early stages of the cancer experience, it appears that medical practitioners and patients are focused on the biomedical aspects of the illness (i.e. curing the cancer). At this time, patients appear to be most concerned with commencing treatment as soon as possible. Thus, further research is required to understand potential barriers at the health practitioner, and patient level that may impact on patients seeking services early in the illness experience.

Providing information about available support services in brochures does not appear to be an effective method to encourage the use of support services. For example, participants - particularly at early stages of their cancer experience - reported that they did not read brochures because they were unsure of their 'relevance' and/or did not want to be overwhelmed with information. Nevertheless, when they were asked to develop recommendations, they suggested that they would prefer to receive information concerning 'relevant' support services directly from those involved with community organisations. Such a one-on-one approach would require considerable personnel and is unlikely to be feasible. Nevertheless, within the following proposal, it may be possible to implement the research participants' recommendations whilst also contributing to the development of further research using the COR theory and concurrently improving access to community services.

(ii) Development of Resource Caravans

Incorporating measures associated with Hobfoll's (2001; 1989; 1988) COR theory, along with quality of life sub-domain scores, may provide an efficacious way of identifying where support and resources are required. Furthermore, such an approach could be used to increase access and referral to community services. Within the COR theory, Hobfoll (2001) offers the term 'resource caravan' to refer to the notion that resources tend to cluster. For example, an individual who has resources in one of the main resource areas (object, condition, personal, energies) is likely to have resources in other areas. In contrast, an individual vulnerable to experience distress is someone who lacks resources in one area as they are also likely to have limited resources in another area. For example, an individual with low self-esteem (personal resource) who is single (condition resource), with limited education (energies resource) is likely to have difficulty accessing social support.

Applied in a literal sense, it would be possible to establish resource caravans where the aim would be to provide a 'broad-based' approach to the provision of resources (Hobfoll, 2001, p.

361). For example, these resource caravans could serve several purposes such as providing resources concerning the prevention of cancer, education about cancer and its impact on people's lives and, information concerning 'resources' available for support. Education at the community level could attempt to highlight incorrect assumptions individuals have concerning the role of positive spirit and survival.

Specifically with reference to improving access to services, these caravans could visit hospitals, shopping centres, schools, and community events. Publicity could be generated to encourage all, including those with cancer and/or survivors of cancer, to visit the caravans for a variety of 'resources'. In each caravan, facilities to conduct research in an on-line format could be established.

Questionnaires relevant to the COR (i.e. The Conservation of Resources Evaluation COR-E; Hobfoll & Lilly, 1993) and FACT-G could be completed on-line and ultimately automated information could be generated that directed patients to the particular and 'relevant' resources available. Other methods could utilise existing infrastructure of community organisations. For example, website links and telephone help services could encourage individuals to find out what resources they might benefit from.

The critical component of such an approach would involve the individual receiving 'relevant' and valued resources that also have the potential to generate the accumulation of additional resources. Ultimately, once a large pool of data is available, it would be possible to score responses and generate a list of relevant services automatically. For example, low scores on the social and family wellbeing scale might indicate that an individual would benefit from being involved in a support group, or a program involving improving communication with family members. Low object resources might suggest referral to resources (if available and relevant) at the government level (i.e. Centrelink). Other programs such as assertiveness

training or the provision of information and or instruction on communicating with health professionals may be suited to those who have low personal resources (e.g., self-esteem). Individuals with low condition (e.g., ill-health) and/or energy resources (i.e. money) may require assistance in accessing the range of services needed to meet their emotional and physical needs.

Initially, it may be necessary to run the project on a smaller scale. For example, volunteers or members from community organisations could collect information from patients regarding their available resources. Data would be collated on an individual basis and the patient provided with information concerning 'relevant' and available services. Periodic follow up with these individuals could attempt to monitor changes in needs and preferred resources required throughout their illness experience.

Implementation of such an approach might also improve understanding concerning the kinds of resources most valued and could possibly lead to the development of new resources (e.g., programs). For instance, based on the results reported in Chapter 7, it appears that the losses experienced by patients extend beyond those measured by generic quality of life measures. For example, in addition to losses in social, physical, and functional domains, patients emphasised pervasive losses associated with their role and/or function in society. Hobfoll's (2001; 1989; 1988) COR theory with its emphasis on understanding stress and coping from an individual-nested-in-tribe perspective (see Chapter 7), appears to be a particularly relevant theory for understanding such pervasive losses. With an emphasis on a range of resources, it also appears to be a particularly useful theory for developing and evaluating the 'relevance' of community programs aimed at reducing the impact of cancer.

The COR theory (Hobfoll, 1988) may also have applicability to the IBS sample. For example, research that combines measures of distress, quality of life and perceptions of coping

resources may increase the specificity with respect to understanding the nature of the disability experienced by IBS patients. Such an approach may also suggest tailored intervention approaches focused on coping skills and gaining needed resources.

10.9 Moving Forward: Developing Integrated Approaches

Developing initiatives aimed to improve the management of chronic illness at the public policy level will not be easy. Chronic illness has been described as a need in search for a system (NSW Health, 2001). Nevertheless, there does appear to be a gap in terms of the initiatives espoused in the literature and public policy recommendations and patients' acceptance and/or perhaps willingness to engage with such initiatives. Thus efforts to develop policy, particularly those involving changes in the way that health services are delivered should involve public consultation. Specifically, further research that assesses for impediments to the implementation of initiatives such as shared care and SDM are needed to assess for the role of psychosocial factors, incorporating assessments of patients' competencies to engage with the health system in a participatory and consumer directed way.

From a researchers perspective there are some small, and yet possibly significant, contributions that can be made in terms of generating theory pertaining to improving strategies in managing chronic illness. Currently, for example, it is difficult to integrate literature and knowledge across disciplines with many advocating for different approaches towards defining evidence base care. Undoubtedly, more empirical studies that directly assess the effectiveness of public policy initiatives on actual empirical measures of health care expenditure and disease burden are necessary. Currently a lack of uptake of approaches precludes reliable evaluations of their effectiveness. Instead, it appears that in the interim studies that focus on understanding potential impediments to the uptake of such approaches are required. Indeed, in doing so, there may be adjustments and/or revisions to such recommendations.

In working towards the development of effective models of health care, it is likely that contributions will come from a variety of disciplines. However, a barrier in terms of integrating this knowledge exists. For example, the dominant approach to research in psychology and medicine involves the use of the hypothetico-deductive model. For instance, within this model, it is difficult to conduct research that incorporates the range of perspectives as is needed when designing initiatives aimed at improving health care. The focus in this model is on reducing information (i.e. reductionist) rather than expanding and building upon knowledge, concepts, and explanations.

In contrast, the use of the constant-comparison method (i.e. grounded theory), with its emphasis on grounding the proposal of theory in empirical data, is a useful way in which the various perspectives of health can be incorporated. Although grounded theory tends to be linked with qualitative research, technically it can be used to incorporate data obtained from a range of sources. Indeed, this is a strength, yet a somewhat overlooked emphasis of the approach.

Grounded theory, although clearly a qualitative method, endeavored [sic] to integrate the strengths inherent in quantitative methods and qualitative approaches ...

Walker & Myrick, 2006, p. 548

The flexibility that exists when generating theory using constant comparative methods enables the incorporation of a range of data sources, and ultimately may provide a more complete account than would have resulted using a hypothetico-deductive model. For instance, as was evident in this thesis, the potential range of factors involved in chronic illness extends from the health policy framework to the implementation of initiatives – and potentially incorporates a range of psychosocial impediments associated with implementation.

Grounded theory as a methodological template

In this thesis, incorporating grounded theory resulted in research that provided a unique perspective into understanding psychosocial aspects associated with chronic illness. Moreover, it generated several hypotheses concerning coping processes, the use of health services, and identified factors that may impact on patients' perceptions of the quality of health care received. Several of the hypotheses generated were contrary to the views and hypotheses proposed in the formal literature. Although these hypotheses need to be subjected to further validation, these insights would not have been gained using a traditional hypothetico-deductive framework. For example, as was argued in Chapter 5, formal theory concerning emotional inhibition failed to provide an adequate explanation of the data emerging from the research reported in this thesis.

It appears that in working towards integrated models of health care, that an integrated approach towards the development of knowledge is required. It seems that the grounded theory may provide an excellent methodological template. Use of the grounded theory potentially enables the incorporation of diverse data across a range of disciplines. This broad and integrated approach may produce some useful insights that may inform the generation of knowledge and theory relevant to improving the management of chronic illness.

Furthermore, although different disciplines have different definitions of what comprises evidence based practice, Meyrick (2006, p. 800) suggests that the emphasis on evidence-based practice by the Government has forced consideration of a wider pool of evidence. Grounded theory, with its ability to consider evidence from a range of data sources appears to be a particular useful methodology.

10.10 Limitations of Research

Specific limitations that apply to the conduct of particular studies have been reviewed within previous chapters. Summarised here are those general limitations that apply to the samples

that comprised the foci of this thesis. The two samples comprising the foci of this thesis were small and potentially not representative of populations of IBS patients, or cancer patients.

For instance, the cancer patients were recruited via an opportunity sample and may differ in significant ways from other cancer patients. Participants who comprised the IBS participants were predominantly women, and indeed no males returned the questionnaire. Thus, results and conclusions drawn from the quantitative data reported are applicable to women only. Moreover, the results with respect to the IBS sample are only applicable to those that attended an appointment with a specialist. As described in Chapter 9, patients were referred from a variety of sources, and so the results reported may be particular to these referral methods.

The use of the term ‘cancer patient’ may have been inappropriate given that many of the patients received their initial diagnosis several years ago. Nevertheless, some of these patients did experience a diagnosis of recurrence and thus are correctly described as patients. Nevertheless, future research is required to assess more precisely how individuals who have once had cancer define themselves. For example, do cancer patients conceive of their condition as one involving ‘a chronic illness’, or do they view themselves as ‘survivors’?

10.11 Conclusion

A comparison of an illness with an organic origin (cancer) versus an illness with no known organic cause (IBS) offered a unique perspective into understanding the role of psychosocial factors in the experience of illness, and enabled contrasts in terms of the nature and extent of perceived disability (i.e. distress and quality of life) in these two groups. In addition to assessing the nature and extent of disability in these two chronic illness groups, a range of other psychosocial issues were explored in this study, including: emotion regulatory strategies (emotional inhibition/expression), communication, support services, patient expectations, satisfaction with medical consultations and health care seeking. Strategies for improving the management of IBS focused on improving doctor-patient communication,

reducing stress and anxiety, implementing strategies focused on improved coping strategies, and providing needed resources. Overall, the findings presented in this thesis have the potential to make important contributions at the health-service delivery level, within the scientific literature and may potentially impact on the development of policy focussed on reducing disease burden by improving the management of chronic illness.³⁸

Recommendations relevant to the cancer sample focused on the provision of a multidisciplinary team approach to treating cancer, facilitating access and use of community support services via application of the COR theory. Although there are distinct strategies that apply to each of the chronic illnesses studied, these recommendations may also be applicable to other chronic illnesses. With a focus on hypothesis generation maintained throughout this thesis, a range of hypotheses and proposals for future research have been documented. Recommendations for moving forward in terms of developing knowledge relevant to implementing effective strategies for managing chronic illness focused on a proposal involving the integration of knowledge across disciplines, incorporating Glaser's (1992) theory as a methodological template.

³⁸ At the time of submission of this thesis, several aspects of this research had been peer reviewed and accepted for presentation at International meetings. A list of these is provided in Appendix M.

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APPENDICES

Appendix A: Amendments to Research Protocol

Ethics Approval

Ethics approval for the conduct of studies reported on in this thesis with respect to the cancer participants was gained from 3 major hospitals located in South Australia, Australia. These included: the Royal Adelaide Hospital (RAH), the Repatriation General Hospital (RGH), and the Flinders Medical Centre (FMC). Ethics approval for the conduct of research relevant to the IBS sample was gained from the Royal Adelaide Hospital.

Informed Consent

All participants were required to provide written informed consent. They were advised that their participation was voluntary and that they could cease their participation, at any time, throughout the duration of the research project.

Participant payment, confidentiality

Participants were not entitled to payment for participation in this research. Participants were also guaranteed of anonymity and confidentiality; thus, all data pertaining to individual participants was coded to ensure the anonymity of participants.

Amendments

Several amendments to the original research protocol occurred during the conduct of this research project. These amendments apply to the cancer sample only. These amendments impacted upon the research project in terms of the sampling methods adopted; the study design and measures incorporated; and the general research philosophy and approach taken. Provided here is essentially a chronology of changes in protocol, along with details

concerning why they were made and how they impacted on the general research approach taken in this thesis.

Initially, the predominant focus of this thesis was going to be on assessing the effectiveness of particular emotion-focussed psychotherapies in reducing distress and improving quality of life. In addition to including psychological measures as outcomes, measures of immune function were also intended to be used. However, due to issues reviewed subsequently, the research emphasis and unfolding of the research changed in focus.

Recruitment Attempts

Initial recruitment attempt – Attempt 1. Approximately 200 information sheets were sent directly to oncologists working in each of the three major hospitals that ethics approval had been sought. In each case, a personal introduction was facilitated and the researcher discussed the nature of the research project either in-person, via telephone or via email correspondence. Note that each information sheet produced for each of the hospitals was slightly different in accord with specific requirements of each of the hospital's ethics committees' requirements. Specifically, there were two differences. First, the Royal Adelaide Hospital insisted that the selection criteria were not to be included in the information sheet (i.e., the ethic's committee deemed that the assessment of suitability should be assessed by the researcher not the participant). Second, the Royal Adelaide Hospital's ethics committee also requested that an explicit warning regarding any potential adverse consequences of the proposed emotion focussed therapy be included.

No patients were referred via this method. A possible reason for non referral was identified by a senior oncologist at one of the hospitals. According to this oncologist, this research would be unlikely to attract direct referral from oncologists unless they were directly involved

with the research project (i.e. their names would appear in subsequent publications developed from this work).

Attempt 2. A further 150 information sheets were hand delivered to waiting areas in each of the hospitals whereby ethics approval was gained. Each information sheet was printed on a brochure for ease of placement into information racks.

One patient was recruited to this study using this method of recruitment.

Attempt 3. An additional large private hospital, with a large cancer centre was contacted, however, despite initial support offered by a senior consultant oncologist, administrative regulations prohibited consultants to participate in research for which there was no direct funding to the hospital. Thus, the oncologist withdrew support.

Attempt 4. The researcher persisted at the methods described above for approximately 8 months, and then amended the research protocol and recruitment methods. Note that two years post-placement of these information sheets into the racks in waiting areas, no further referrals have been received. In fact, the majority of information sheets remain in the information racks. Thus, the recruiting method was amended.

Publicity was generated via the University of Adelaide's marketing department. Specific details were reviewed in Chapter 1.

Amendments and impact on research at a general level

Experiences and knowledge gained from the early phases of this research, (as evidenced in the type and nature of the amendments reviewed) substantially changed the framework from which this research was embedded. For example, initially a researcher-driven framework was adopted whereby the focus was to assess the efficacy of emotion-focussed psychotherapies using a randomised control designed study.

However, considerable knowledge was gained during the initial stage of the research and several possible interpretations concerning difficulties encountered can be drawn. First,

given the lack of enquiries received following the dissemination of the information sheets, it appeared possible that patient's acceptability of such an approach was low. However, it was unclear whether the style of therapy (i.e. emotion focussed) or perhaps the invasiveness of data collection (i.e. blood collection) was impacting on acceptability. Thus, it appeared critical that within the context of this research an assessment of patient's acceptability of the proposed therapy be included.

The revised research focus incorporated principles relevant to Participatory Action Research, and Grounded Theory. Rather than imposing a particular research focus on participants (i.e. evaluating the efficacy of emotion-focused therapy), patients would be encouraged to share their knowledge and experience with respect to their cancer experiences and furthermore would be encouraged to contribute to the emerging research process.

Amendments to protocol

Following the conduct of 3 complete screening interviews, substantial revisions were made to the research protocol. For instance, when conducting the screening interview, and taking general phone enquiries, it was clear that some of the selection criteria were prohibitive. Many patients, for instance, had other chronic illnesses (heart disease, diabetes, arthritis) and on the basis of the protocol's criteria, these patients would be ineligible to participate. Patients also had a variety of cancers (i.e. not always solid neoplasms), the time since diagnosis was regularly greater than 12 months, and patients were not always aware of the particular stage of cancer diagnosis. Initially, the screening interview sought to establish whether potential participants met the following selection and exclusion criteria:

Selection criteria:

- Aged 18-74 years;

- Received a diagnosis of Stage I, or II cancer (solid neoplasm) within the past 12 months;
- Score more than 4 using the General Health Questionnaire (GHQ-12)
- A minimum of two months must have elapsed since surgery, chemotherapy or radiation therapy;
- Speak fluent English;
- Have no apparent intellectual impairment;
- Reside within the Adelaide metropolitan area; and
- Be able to attend psychological treatment on a weekly basis (for 1 hour) over an 8 week period.

Exclusion criteria

- Have a concurrent DSM-IV psychotic disorder;
- Have a GHQ score less than 4;
- Are physically unwell at the time of testing and/or are physically unable to attend trial;
- Have a diagnosis of Heart Disease, Diabetes, Rheumatoid Arthritis, Addison's disease, Cushing's Disease or Lupus;
- Are taking medication that suppresses the immune system;
- Are pregnant or breast feeding;
- Have an infectious disease such as HIV, HBV, HCV; and
- Have participated in a previous emotion-focused psychotherapy trial.

Withdrawal criteria included:

- Participant withdrawal;
- Withdrawal by doctor if due to a concomitant illness and/or it is not thought reasonable for the participant to continue; and/or
- Completion of study.

There were additional problems encountered during the screening interview. For instance, whilst some potential participants were keen to share experiences about their cancer experience, they were unsure if they wanted to, had the time, or need to participate in the proposed 8 week emotion-focused therapy trial. Some potential participants were also unsure if they wanted to commit the time that would be required to complete the therapy and have all proposed blood assessments taken. The intervention was subsequently changed to a 4 week program.

Also, when screening levels of distress, using the GHQ, difficulties in terms of gaining 'valid' responses was experienced. For example, when responding to GHQ questions (posed in an interview format) patients were responding to many items as "same as usual", however, this did not appear to capture their true level of distress, as was evident by accompanying comments made by patients or by observations made by the researcher (patient's crying when recounting experiences), or responses on the SCID. It appeared that the standard term of reference provided to patients for each GHQ item (e.g., the last few weeks) was problematic. Some patients, for example, had felt distressed for considerable time and thus this term of reference did not appear valid.

Furthermore, researcher observations during telephone calls received, and during the screening interviews conducted revealed that patients had specific experiences and a wealth of knowledge with respect to their illness experience. Patients, for instance, were keen to describe their experiences with respect to diagnosis (and the accompanying emotions experienced), and communication/support experiences relevant to families and medical professionals. Within the original research protocol, no specific methodology had been included to capture this information. In other words, patients' were disclosing this information and without a particular structure, this data would have been lost. This data was

judged by the researcher to be important in terms of developing a holistic understanding of patients' experiences with cancer.

Such an understanding was judged to be important in terms of providing a context and framework that might enrich and inform knowledge gained from results obtained in subsequent phases of the research. In addition, it appeared that the application of a mixed methods approach to this research would contribute to producing a valid understanding of the nature of patient needs. For instance, in light of the difficulties noted with respect to the validity of patients' responses on the GHQ measure, there appeared to be possible benefits in terms of asking similar questions, or attempting to assess similar constructs using multiple methods.

Finally, it was evident from the first three interviews that the Structured Clinical Interview for DSM-IV Axis 1 Disorders (SCID, Spitzer, Miriam, Williams & Janet (1998) was imposing a greater patient burden than was intended, and indeed as had been stated on the information sheet provided to participants. In each of the first three interviews conducted, the time taken to complete the SCID exceeded the time specified by an additional 1 – 2 hours.

Amendments to protocol. Following the conduct of first three interviews and in consideration of the difficulties encountered, and the knowledge gained from the research process, amendments to the protocol were prepared and lodged with the three hospital research ethics committees. Changes included:

- 1) Removal of certain inclusion criteria so that patients could have-
 - a. diagnosis occurring > 12 months ago; other types of cancers (i.e. not necessarily solid neoplasms); co-morbid chronic illness (e.g., heart disease, diabetes, arthritis).

- 2) Inclusion of a ‘research interview’ that included specific interview questions to capture patients’ perspectives of their illness. In addition, specific questions were included to assess the acceptability of the emotion-focussed therapy proposed
- 3) Inclusion of an additional measure of distress (Depression & Anxiety & Stress Scales, DASS, Lovibond & Lovibond, 1995)
- 4) Finally, to remain consistent with the information sheet (and approved research protocol), the SCID clinical interview was replaced with the MINI (Sheehan et al., 1998) as was more consistent with the timings (as per the research protocol).
- 5) Also note that a subsequent decision to delete blood measures was based on the changes to the research focus.

Procedure whilst awaiting ethics clearance

All changes to the protocol were approved by each of the hospital’s ethics committees. This process delayed the commencement of further interviews for a period of approximately 2 months. Whilst waiting for approvals, all patients were sent information sheets. Patients were sent copies of the Royal Adelaide Hospital’s information sheet, as participants were not patients from the Flinders Medical Centre or the Repatriation General Hospital. Typically, participants were patients at the Royal Adelaide Hospital or other smaller private hospitals located throughout Adelaide. Note that the one patient recruited via an information brochure received her treatment at the Flinders Medical Centre.

Once approval was received, potential participants were re-contacted and invited to attend an interview with the researcher. The interview comprised of the ‘screening interview’ and a clinical interview to assess for mental disorder according to DSM-IV criteria, and a ‘general research interview’. Note that data relevant to the screening interview (as described above) was still collected, however, the data obtained (e.g., chronic illnesses, dates of diagnosis, GHQ scores) was not used to exclude participants.

Appendix B: Information Sheet and Informed Consent: Cancer Sample



ROYAL ADELAIDE HOSPITAL

PATIENT INFORMATION SHEET

RAH PROTOCOL: 050919

“Emotion-Focused Psychotherapy: Can it Improve Quality of Life and Immune **Function in Cancer Patients?**”

Investigators

Ms Vikki Knott
Professor Deborah Turnbull
Professor Ian Olver
Professor Tony Winefield
Associate Professor Caroline Smith
Dr Jane Blake-Mortimer

The purpose of this study is to see if psychotherapy that focuses on expressing emotion is helpful to cancer patients. In particular, we will assess your level of stress, quality of life and immune functioning.

We invite you to contact us to confirm your eligibility in this study:

If you agree to participate in this study you will be asked to:

1. Complete an initial screening interview (by telephone) to confirm your eligibility to participate in this study. This will take about 10 minutes. If eligible, then you will be asked to complete an interview “in-person”. This will take about 40 minutes.
2. Complete a questionnaire (paper and pencil style) on three separate occasions. This will take approximately 90 minutes, on each occasion, to complete. Please note that the questionnaire can be taken home with you and completed over seven days.
3. Give a blood (32mls) and saliva sample to measure your immune functioning on three separate occasions. All blood and saliva samples will be taken by a Registered Nurse.

You may also be asked to:

4. Attend a therapy session for 1 hour each week for 8 weeks. Therapy will be delivered on an individual basis at the University of Adelaide. Not all volunteers will receive the psychotherapy, and a process known as “randomization” will be used to allocate participants to either the “psychotherapy group”, or the “control group”.

Potential Risks

1. Bruising: Please note that some individuals may be at risk of experiencing slight bruising when providing a blood sample. This risk is increased in individuals taking medications that include blood thinning agents such as aspirin, warfarin, NSAID and ginkgo. As a precaution, individuals taking this medication must inform the researchers and provide approval from

their general practitioner to have your blood taken. You will not be asked to discontinue this medication.

2. Emotion-focused psychotherapy: Dealing with your emotional experiences with respect to your cancer diagnosis, or other distressing events, may invoke particularly strong emotions and some transient increases in distress may be experienced. However, we do not expect for you to experience sudden and overwhelming levels of distress. In the event that you experience distress to the extent that you feel the therapy session is leading to a decrease in your coping abilities with respect to your cancer diagnosis, then the therapy session will be stopped. You will immediately be referred for professional counselling with a Registered Psychologist to discuss your intense emotions and to resolve any distress experienced as a result of the therapy sessions.

Participation voluntary/confidential

Your participation in this project is completely voluntary and the information you supply will be strictly confidential. All information collected will have all names removed and the results of the study will be reported anonymously. You are free to withdraw your participation from the study at any time. Your medical care will not be affected if you decide not to participate or you decide to withdraw from the study.

Informed consent

Before commencing participation in this study, you will be required to complete a Consent Form. In this instance, you will be required to provide your name, however, this information will not be linked to any information you supply.

May not benefit from study

Participation in this study may not be associated with any direct benefits to you. Even if you are allocated to the psychotherapy group, the effectiveness of these therapies has not yet been proven.

Further information/complaints

This study has been reviewed by the Research Ethics Committee at the Royal Adelaide Hospital. If you have any general questions regarding participating in this study you may contact Ms Vikki Knott on 8303 6785 (between 9am and 5pm). If you have any questions regarding the ethical aspects of this study, please contact the Chairperson of the Ethics Committee at the Royal Adelaide Hospital on (08) 8222 4139.

For further information, and/or to confirm your eligibility to participate, please contact Vikki Knott on 8303 6785, or email: vikki.knott@adelaide.edu.au



ROYAL ADELAIDE HOSPITAL

INFORMED CONSENT

Protocol Title: Evaluation of the Efficacy of Emotion-Focused Psychotherapy for Reducing Distress and Improving Quality of Life and Immune Function in Cancer Patients.

Investigators

Ms Vikki Knott
Professor Deborah Turnbull
Professor Ian Olver
Professor Tony Winefield
Associate Professor Caroline Smith
Dr Jane Blake-Mortimer

1. The nature and purpose of the research project has been explained to me. I understand it, and agree to take part.
2. I understand that I may not directly benefit from taking part in the study.
1. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
2. I understand that I can withdraw from the study at any stage and that this will not affect my medical care, now or in the future.
3. I have had the opportunity to discuss taking part in this investigation with a family member or friend.
4. I have read the Information Sheet and understand the potential risks described.

Name of Participant (printed)

Signature of Participant

Date

I certify that I have explained the study to the patient/volunteer and consider that he/she understands what is involved.

Name Investigator (printed)

Signature of Investigator

Date

Appendix C: Information Sheet and Informed Consent: IBS Sample



ROYAL ADELAIDE HOSPITAL

PATIENT INFORMATION SHEET

Protocol Title: Improving the management of chronic illness: Understanding the expectations and needs of IBD/IBS patients.

Investigators
Ms Vikki Knott
Dr Jane Andrews
Professor Deborah Turnbull
Professor Gerald Holtman

The purpose of this study is to understand the nature of your experiences and expectations prior to meeting with a specialist gastroenterologist at the Royal Adelaide Hospital. Our aim is to identify any unmet needs with respect to the diagnosis and/or management of your illness.

If you agree to participate in this study you will be asked to:

- Complete an interview at the Royal Adelaide Hospital. The interview will be tape recorded and the data transcribed by the researchers. The interview will take approximately 30 minutes.
- Complete a paper and pencil questionnaire. This will take between 15 and 30 minutes to complete.
- Participate in a focus group discussion with other patients with IBD/IBS and gastroenterology specialists. The focus group will take approximately 90 minutes. The session will be recorded via audio tape and the results transcribed by the researchers.

Potential Risks

Nil

Participation voluntary/confidential

Your participation in this project is completely voluntary and the information you supply will be strictly confidential. All information collected will have all names removed and the results of the study will be reported anonymously. You are free to withdraw your participation from the study at any time. Your medical care will not be affected if you decide not to participate or you decide to withdraw from the study.

Informed consent

Before commencing participation in this study, you will be required to complete a Consent Form (see attached). In this instance, you will be required to provide your name, however, this information will not be linked to any information you supply.

May not benefit from study

Participation in this study may not be associated with any direct benefits to you.

Further information/complaints

This study has been reviewed by the Research Ethics Committee at the Royal Adelaide Hospital. If you have any general questions regarding participating in this study you may contact Ms Vikki Knott on 8303 6785 (between 9am and 5pm). If you have any questions regarding the ethical aspects of this study, please contact the Chairperson of the Ethics Committee at the Royal Adelaide Hospital on (08) 8222 4139.



ROYAL ADELAIDE HOSPITAL

INFORMED CONSENT

Investigators
Ms Vikki Knott
Dr Jane Andrews
Professor Deborah Turnbull
Professor Gerald Holtman

The nature and purpose of the research project has been explained to me. I understand it, and agree to take part.

I understand that I may not directly benefit from taking part in the study.

I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.

I understand that I can withdraw from the study at any stage and that this will not affect my medical care, now or in the future.

1. I have had the opportunity to discuss taking part in this investigation with a family member or friend.
2. I have read the Information Sheet and understand the potential risks described.

Name of Participant (printed)

Signature of Participant Date

I certify that I have explained the study to the patient/volunteer and consider that he/she understands what is involved.

Name Investigator (printed)

Signature of Investigator Date

Appendix D: Intercorrelations among study variables for Chapter 2 (IBS and Cancer)

Table 1. IBS Sample: Intercorrelations FACT-G and DASS (**. Correlation is significant at the 0.01 level (2-tailed). *. Correlation is significant at the 0.05 level (2-tailed)

	1	2	3	4	5	6	7	8	0	10	11
1. AGE											
2. Religious Involvement	.626 .022 13										
3. Months since Diagnosis	.543 .166 8										
4. PWB	.007 .982 13	-.320 .286 13	-.446 .269 8								
5. SWB	-.208 .494 13	.043 .889 13	.128 .762 8	.008 .979 13							
6. EWB	.007 .981 13	.139 .650 13	-.085 .842 8	.219 .473 13	.248 .415 13						
7. FWB	.037 .903 13	.016 .960 13	-.414 .308 8	.584 .036 13	.505 .078 13	.257 .397 13					
8. SPI2	.401 .174 13	.388 .190 13	.164 .698 8	.365 .221 13	.572 .041 13	.561 .046 13	.746** .003 13				
9. FACT-G	-.051 .868 13	-.081 .792 13	-.340 .410 8	.720** .005 13	.601* .030 13	.550 .052 13	.875** .000 13	.789** .001 13			
10. Stress	.155 .614 13	.274 .365 13	.512 .195 8	-.566* .044 13	-.423 .150 13	-.448 .124 13	-.554* .049 13	-.475 .101 13	-.723** .005 13		
11. Anxiety	.095 .758 13	.276 .362 13	.604 .113 8	-.576* .039 13	-.225 .461 13	-.492 .088 13	-.503 .080 13	-.391 .187 13	-.653* .016 13	.957** .000 13	
12. Depression	.047 .879 13	-.085 .783 13	.484 .224 8	-.398 .178 13	-.484 .094 13	-.285 .346 13	-.533 .061 13	-.434 .138 13	-.617* .025 13	.804** .001 13	.766** .002 13

Table 2. Cancer Sample: Intercorrelations FACT-G and DASS (**. Correlation is significant at the 0.01 level (2-tailed). *. Correlation is significant at the 0.05 level (2-tailed)

	1	2	3	4	5	6	7	8	9	10	11	12
1. AGE	1											
2. Months since Diagnosis	.037 .897 15	1										
3. Date of Last Treatment/Months in Remission	-.003 .992 15	.959** .000 15	1									
4. Religious Involvement	.230 .411 15	.172 .540 15	.300 .277 15	1								
5. PWB	.110 .696 15	-.282 .308 15	-.260 .349 15	.169 .547 15	1							
6. SWB	-.137 .627 15	-.577 .024 15	-.609 .016 15	-.695** .004 15	-.056 .843 15	1						
7. EWB	-.167 .553 15	-.426 .113 15	-.383 .158 15	-.024 .931 15	.139 .621 15	.250 .368 15	1					
8. FWB	-.057 .841 15	-.581 .023 15	-.500 .058 15	.103 .716 15	.580 .024 15	.081 .774 15	.714** .003 15	1				
9. SPI2	.047 .867 15	-.151 .591 15	.000 1.000 15	.628 .012 15	.207 .460 15	-.338 .217 15	.345 .207 15	.449 .093 15	1			
10. FACT-G	-.092 .745 15	-.718** .003 15	-.678** .005 15	-.218 .436 15	.602 .018 15	.531 .042 15	.727** .002 15	.851** .000 15	.201 .472 15	1		
11. Stress	.168 .549 15	.299 .278 15	.264 .342 15	.339 .216 15	-.446 .095 15	-.246 .376 15	-.584 .022 15	-.671** .006 15	-.221 .430 15	-.704** .003 15	1	
12. Anxiety	.051 .856 15	.435 .105 15	.457 .087 15	.336 .220 15	-.506 .055 15	-.337 .220 15	-.367 .179 15	-.518** .048 15	-.245 .379 15	-.643** .010 15	.825** .000 15	1
13. Depression	.086 .761 15	.389 .152 15	.333 .225 15	.024 .933 15	-.651** .009 15	-.035 .902 15	-.456 .088 15	-.742** .002 15	-.390 .150 15	-.676** .006 15	.834** .000 15	.828** .000 15

Appendix E: Intercorrelations among study variables for Chapter 3 (Cancer only)

Table 1. Intercorrelations IES-R, DASS, and FACT-G, cancer sample (Chapter 3)

	1	2	3	4	5	6	7	8	13	14	15
1. Age											
2. religion involvement	.259 .332 16										
3. Months_Diagnosis	.027 .921 16	.164 .543 16									
4. Avoidance	-.226 .400 16	-.054 .844 16	.035 .898 16								
5. Intrusions	.205 .447 16	.455 .076 16	.351 .182 16	.540* .031 16							
6. Hyper-arousal	-.088 .745 16	.153 .572 16	.294 .269 16	.634** .008 16	.733** .001 16						
7. IES	.013 .961 16	.258 .334 16	.238 .374 16	.849** .000 16	.903** .000 16	.783** .000 16					
8. IES_R	-.022 .935 16	.234 .382 16	.271 .311 16	.817** .000 16	.890** .000 16	.902** .000 16	.975** .000 16				
9. Factg	-.073 .787 16	-.206 .445 16	-.718** .002 16	-.357 .175 16	-.604* .013 16	-.778** .000 16	-.561* .024 16	-.668** .005 16			
10. stress	.163 .548 16	.335 .205 16	.299 .260 16	.407 .118 16	.664** .005 16	.828** .000 16	.624** .010 16	.730** .001 16	-.703** .002 16		
11. anxiety	.050 .855 16	.332 .209 16	.435 .093 16	.435 .092 16	.594* .015 16	.714** .002 16	.595* .015 16	.669** .005 16	-.642** .007 16	.825** .000 16	
12. depression	.083 .760 16	.023 .931 16	.389 .137 16	.392 .134 16	.373 .155 16	.648** .007 16	.434 .093 16	.533* .034 16	-.675** .004 16	.834** .000 16	.828** .000 16

** . Correlation is significant at the 0.01 level (2-tailed). * Correlation is significant at the 0.05 level (2-tailed)

Appendix F: Correlations Coping Styles, Emotion Regulation and Distress and Quality of Life

Table 1. Inter-correlations coping styles and emotion regulating measures (Chapter 4)

	1	2	3	4	5	6	7	8	9	10	11	12
1. Anxious Preoccupation	1											
	.16											
2. Helpless-Hopeless	.631**	1										
	.009	.16										
3. Fighting Spirit	-.328	-.303	1									
	.214	.255	.16									
4. Need for Harmony	.446	.270	-.189	1								
	.083	.311	.482	.16								
5. Self-Sacrifice	.242	.150	-.373	.846**	1							
	.367	.579	.155	.000	.16							
6. Rationality/Emotional Def	.362	.369	-.370	.233	.096	1						
	.168	.159	.158	.385	.723	.16						
7. WAI: Distress	.236	.574*	-.476	.098	.150	.625**	1					
	.379	.020	.062	.717	.579	.010	.16					
8. Emotion Processing	.348	.290	.001	-.110	-.405	.671**	.339	1				
	.187	.276	.998	.685	.119	.004	.199	.16				
9. Emotional Expression	.037	.314	-.041	-.189	-.216	.556*	.454	.685**	1			
	.891	.236	.880	.483	.423	.025	.077	.003	.16			
10. CES: Anger	.316	.149	-.283	.304	.269	.223	.244	-.138	-.497	1		
	.251	.596	.307	.270	.331	.425	.380	.625	.059	.15		
	.15	.15	.15	.15	.15	.15	.15	.15	.15	.15		
11. CES: Anxiety	.247	.229	-.323	.357	.548*	.225	.362	-.200	-.104	.696**	1	
	.374	.412	.240	.192	.035	.421	.185	.475	.712	.004	.15	
	.15	.15	.15	.15	.15	.15	.15	.15	.15	.15	.15	
12. CES: Depression	.574*	.511	-.249	.313	.247	.365	.228	.207	-.021	.710**	.694**	1
	.025	.052	.370	.255	.376	.181	.414	.459	.942	.003	.004	.15
	.15	.15	.15	.15	.15	.15	.15	.15	.15	.15	.15	.15
13. CES: Total	.411	.316	-.321	.364	.402	.296	.314	-.065	-.246	.904**	.896**	.882**
** Correlation is significant at the 0.01 level (2-tailed). * Correlation is significant at the 0.05 level (2-tailed)	.128	.251	.243	.183	.137	.283	.255	.818	.377	.000	.000	.000
	.15	.15	.15	.15	.15	.15	.15	.15	.15	.15	.15	.15

Table 2. Table of inter-correlations: MAC coping styles, distress and quality of life (Chapter 4)

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Anxious Preoccupation	1 16														
2. Helpless-Hopeless	.631** .009 16														
3. Fighting Spirit	-.328 .214 16	-.303 .255 16													
4. Age	-.385 .141 16	-.145 .592 16	-.244 .363 16												
5. Physical Wellbeing	-.380 .147 16	-.320 .227 16	.255 .341 16	.176 .514 16											
6. Social and Family Wellbeing	-.100 .712 16	-.153 .573 16	.136 .616 16	.114 .675 16	-.033 .904 16										
7. Emotional Wellbeing	-.616* .011 16	-.585* .017 16	.657** .006 16	.155 .566 16	.140 .606 16	.251 .348 16									
8. Family Wellbeing	-.616* .011 16	.676** .004 16	.474 .063 16	.102 .707 16	.490 .054 16	.066 .808 16	.697** .003 16	1 16							
9. Spiritual Wellbeing	-.136 .614 16	-.010 .971 16	.382 .144 16	.067 .806 16	.221 .410 16	-.330 .211 16	.346 .189 16	.424 .102 16							
10. DASS: Stress	.301 .257 16	.379 .147 16	-.424 .101 16	.163 .548 16	-.427 .099 16	-.246 .359 16	-.584* .017 16	.659** .005 16	-.220 .413 16						
11. DASS: Anxiety	.101 .710 16	.274 .305 16	-.367 .163 16	.050 .855 16	-.484 .058 16	-.336 .203 16	-.367 .163 16	-.509* .044 16	-.244 .363 16	.825** .000 16					
12. DASS: Depression	.322 .223 16	.348 .187 16	-.335 .204 16	.083 .760 16	.623** .010 16	-.035 .898 16	-.455 .076 16	.729** .001 16	-.389 .136 16	.834** .000 16	.828** .000 16				
13. Months since diagnosis	.414 .111 16	.294 .269 16	-.358 .174 16	.027 .921 16	-.280 .294 16	.578* .019 16	-.427 .099 16	-.565* .023 16	-.153 .571 16	.299 .260 16	.435 .093 16	.389 .137 16			
14. IES-R: Avoidance	.144 .596 16	.060 .826 16	-.239 .373 16	.226 .400 16	-.335 .204 16	-.135 .619 16	-.205 .447 16	-.283 .288 16	.505* .046 16	.407 .118 16	.435 .092 16	.392 .134 16	.035 .898 16		
15. IES-R: Intrusions	.241 .368 16	.112 .681 16	-.440 .088 16	.205 .447 16	-.135 .617 16	.519* .040 16	-.567* .022 16	-.399 .125 16	-.216 .421 16	.664** .005 16	.594* .015 16	.373 .155 16	.351 .182 16	.540* .031 16	
16. IES-R: Hyperarousal	.455 .077 16	.538* .032 16	-.467 .068 16	.088 .745 16	-.522* .038 16	-.301 .257 16	.624** .010 16	.672** .004 16	-.411 .114 16	.828** .000 16	.714** .002 16	.648** .007 16	.294 .269 16	.634** .008 16	.733** .001 16

** . Correlation is significant at the 0.01 level (2-tailed). * Correlation is significant at the 0.05 level (2-tailed)

Table 3. Intercorrelations: Weinberger Adjustment Inventory, distress and quality of life.

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. AGE	1													
2. Physical wellbeing	.176 .514 16													
3. Social and family wellbeing	-.114 .675 16	-.033 .904 16												
4. Emotional wellbeing	-.155 .566 16	.140 .606 16	.251 .348 16											
5. Functional wellbeing	-.102 .707 16	.490 .054 16	.066 .808 16	.697** .003 16										
6. Spiritual wellbeing	.067 .806 16	.221 .410 16	-.330 .211 16	.346 .189 16	.424 .102 16									
7. DASS: Stress	.163 .548 16	-.427 .099 16	-.246 .359 16	-.584* .017 16	.659** .005 16	-.220 .413 16								
8. DASS: Anxiety	.050 .855 16	-.484 .058 16	-.336 .203 16	-.367 .163 16	-.509* .044 16	-.244 .363 16	.825** .000 16							
9. DASS: Depression	.083 .760 16	.623** .010 16	-.035 .898 16	-.455 .076 16	.729** .001 16	-.389 .136 16	.834** .000 16	.828** .000 16						
10. Months since diagnosis	.027 .921 16	-.280 .294 16	.578* .019 16	-.427 .099 16	-.565* .023 16	-.153 .571 16	.299 .260 16	.435 .093 16	.389 .137 16					
11. IES-R: Avoidance	-.226 .400 16	-.335 .204 16	-.135 .619 16	-.205 .447 16	-.283 .288 16	-.505* .046 16	.407 .118 16	.435 .092 16	.392 .134 16	.035 .898 16				
12. IES-R: Intrusions	.205 .447 16	-.135 .617 16	.519* .040 16	-.567* .022 16	-.399 .125 16	-.216 .421 16	.664** .005 16	.594* .015 16	.373 .155 16	.351 .182 16	.540* .031 16			
13. IES-R: Hyperarousal	-.088 .745 16	-.522* .038 16	-.301 .257 16	.624** .010 16	.672** .004 16	-.411 .114 16	.828** .000 16	.714** .002 16	.648** .007 16	.294 .269 16	.634** .008 16	.733** .001 16		
14. WAI: Distress	.160 .555 16	-.389 .136 16	-.373 .154 16	-.601* .014 16	-.601* .014 16	-.220 .412 16	.873** .000 16	.870** .000 16	.744** .001 16	.349 .185 16	.355 .177 16	.608* .013 16	.835** .000 16	
15. WAI: Restraint	.142 .600 16	.120 .658 16	.049 .856 16	-.122 .652 16	-.400 .125 16	.127 .640 16	.410 .115 16	.294 .269 16	.369 .159 16	-.083 .761 16	.260 .331 16	.188 .485 16	.205 .446 16	.271 .310 16

** . Correlation is significant at the 0.01 level (2-tailed). * Correlation is significant at the 0.05 level (2-tailed)

Table 4: Intercorrelations: Lifestyle Defence Mechanism Inventory, distress and quality of life

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Age	1														
2. Physical wellbeing	.176 .514 16														
3. Social and family wellbeing	-.114 .675 16	-.033 .904 16													
4. Emotional wellbeing	-.155 .566 16	.140 .606 16	.251 .348 16												
5. Functional wellbeing	-.102 .707 16	.490 .054 16	.066 .808 16	.697** .003 16											
6. Spiritual wellbeing	.067 .806 16	.221 .410 16	-.330 .211 16	.346 .189 16	.424 .102 16										
7. DASS: Stress	.163 .548 16	-.427 .099 16	-.246 .359 16	-.584* .017 16	.659** .005 16	-.220 .413 16									
8. DASS: Anxiety	.050 .855 16	-.484 .058 16	-.336 .203 16	-.367 .163 16	-.509* .044 16	-.244 .363 16	.825** .000 16								
9. DASS: Depression	.083 .760 16	.623** .010 16	-.035 .898 16	-.455 .076 16	.729** .001 16	-.389 .136 16	.834** .000 16	.828** .000 16							
10. Months since Diagnosis	.027 .921 16	-.280 .294 16	.578* .019 16	-.427 .099 16	-.565* .023 16	-.153 .571 16	.299 .260 16	.435 .093 16	.389 .137 16						
11. IER: Avoidance	-.226 .400 16	-.335 .204 16	-.135 .619 16	-.205 .447 16	-.283 .288 16	.505* .046 16	.407 .118 16	.435 .092 16	.392 .134 16	.035 .898 16					
12. IER: Intrusions	.205 .447 16	-.135 .617 16	.519* .040 16	-.567* .022 16	-.399 .125 16	-.216 .421 16	.664** .005 16	.594* .015 16	.373 .155 16	.351 .182 16	.540* .031 16				
13. IER: Hyperarousal	.088 .745 16	-.522* .038 16	-.301 .257 16	.624** .010 16	.672** .004 16	-.411 .114 16	.828** .000 16	.714** .002 16	.648** .007 16	.294 .269 16	.634** .008 16	.733** .001 16			
14. LDMI: Need for Harmony	-.126 .643 16	-.242 .366 16	.470 .066 16	-.324 .221 16	-.405 .120 16	-.363 .167 16	.153 .571 16	.100 .712 16	.229 .394 16	-.016 .954 16	-.119 .661 16	.053 .846 16	.243 .365 16		
15. LDMI: Self sacrifice	-.211 .432 16	-.227 .397 16	.488 .055 16	-.295 .267 16	-.175 .517 16	-.491 .054 16	.094 .728 16	.180 .504 16	.181 .504 16	.154 .569 16	.060 .825 16	.031 .910 16	.241 .369 16	.846** .000 16	
16. LDMI: Rationality /Emotional Defensiveness	.245 .360 16	-.165 .542 16	-.266 .320 16	-.560* .024 16	-.582* .018 16	.064 .815 16	.747** .001 16	.607* .013 16	.698** .003 16	.283 .288 16	.077 .777 16	.398 .127 16	.461 .072 16	.233 .385 16	.096 .723 16

** . Correlation is significant at the 0.01 level (2-tailed). * Correlation is significant at the 0.05 level (2-tailed)

Table 5. Intercorrelations: CES, distress and quality of life.

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1. Age	1															
2. Physical wellbeing	.176 .514 16															
3. Social and family wellbeing	-.114 .675 16	-.033														
4. Emotional wellbeing	-.155 .566 16	.140	.251													
5. Functional wellbeing	-.102 .707 16	.490	.066	.697**												
6. Spiritual wellbeing	.067 .806 16	.221	-.330	.346	.424											
7. DASS: Stress	.163 .548 16	-.427	-.246	-.584*	.659**	-.220										
8. DASS: Anxiety	.050 .855 16	-.484	-.336	-.367	-.509*	-.244	.825**									
9. DASS: Depression	.083 .760 16	.623**	-.035	-.455	.729**	-.389	.834**	.828**								
10. Months since Diagnosis	.027 .921 16	-.280	.578*	-.427	-.565*	-.153	.299	.435	.389							
11. IER: Avoidance	-.226 .400 16	-.335	-.135	-.205	-.283	-.505*	.407	.435	.392	.035						
12. IER: Intrusions	.205 .447 16	-.135	.519*	-.567*	-.399	-.216	.664**	.594*	.373	.351	.540*					
13. IER: Hyperarousal	-.088 .745 16	-.522*	-.301	.624**	.672**	-.411	.828**	.714**	.648**	.294	.634**	.733**				
14. CES: Anger	.070 .804 15	-.382	.107	-.073	-.487	.706**	.249	.342	.531*	.385	.327	-.004	.293			
15. CES: Anxiety	-.174 .534 15	-.452	.424	-.126	-.296	-.582*	.387	.362	.546*	-.136	.443	-.044	.393	.696**		
16. CES: Depression	-.149 .596 15	-.517*	.214	-.178	-.496	-.254	.198	.152	.503	.107	.147	-.239	.233	.710**	.694**	
17. CES: Total	-.145 .606 15	-.499	.279	-.137	-.473	-.592*	.315	.327	.590*	.136	.351	-.097	.347	.904**	.896**	.882**

** . Correlation is significant at the 0.01 level (2-tailed). * Correlation is significant at the 0.05 level (2-tailed)

Table 6: Intercorrelations: Emotional Approach Coping Scale, distress and quality of life

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. Age	1													
	.16													
2. Physical wellbeing	.176													
	.514													
	.16													
3. Social and family wellbeing	-.114	-.033												
	.675	.904												
	.16	.16												
4. Emotional wellbeing	-.155	.140	.251											
	.566	.606	.348											
	.16	.16	.16											
5. Functional wellbeing	-.102	.490	.066	.697**										
	.707	.054	.808	.003										
	.16	.16	.16	.16										
6. Spiritual wellbeing	.067	.221	-.330	.346	.424									
	.806	.410	.211	.189	.102									
	.16	.16	.16	.16	.16									
7. DASS: Stress	.163	-.427	-.246	-.584*	-.659**	-.220								
	.548	.099	.359	.017	.005	.413								
	.16	.16	.16	.16	.16	.16								
8. DASS: Anxiety	.050	-.484	-.336	-.367	-.509*	-.244	.825**							
	.855	.058	.203	.163	.044	.363	.000							
	.16	.16	.16	.16	.16	.16	.16							
9. DASS: Depression	.083	-.623**	-.035	-.455	-.729**	-.389	.834**	.828**						
	.760	.010	.898	.076	.001	.136	.000	.000						
	.16	.16	.16	.16	.16	.16	.16	.16						
10. Months since Diagnosis	.027	-.280	-.578*	-.427	-.565*	-.153	.299	.435	.389					
	.921	.294	.019	.099	.023	.571	.260	.093	.137					
	.16	.16	.16	.16	.16	.16	.16	.16	.16					
11. IER: Avoidance	-.226	-.335	-.135	-.205	-.283	-.505*	.407	.435	.392	.035				
	.400	.204	.619	.447	.288	.046	.118	.092	.134	.898				
	.16	.16	.16	.16	.16	.16	.16	.16	.16	.16				
12. IER: Intrusions	.205	-.135	-.519*	-.567*	-.399	-.216	.664**	.594*	.373	.351	.540*			
	.447	.617	.040	.022	.125	.421	.005	.015	.155	.182	.031			
	.16	.16	.16	.16	.16	.16	.16	.16	.16	.16	.16			
13. IER: Hyperarousal	-.088	-.522*	-.301	-.624**	-.672**	-.411	.828**	.714**	.648**	.294	.634**	.733**		
	.745	.038	.257	.010	.004	.114	.000	.002	.007	.269	.008	.001		
	.16	.16	.16	.16	.16	.16	.16	.16	.16	.16	.16	.16		
14. Emotional Expression	.226	-.200	-.227	-.273	-.162	.523*	.499*	.369	.362	-.100	-.043	.224	.233	
	.400	.457	.398	.307	.550	.038	.049	.160	.168	.711	.873	.404	.386	
	.16	.16	.16	.16	.16	.16	.16	.16	.16	.16	.16	.16	.16	
15. Emotion Processing	.152	-.202	-.427	-.195	-.293	.597*	.487	.291	.359	.269	-.245	.225	.195	.685**
	.575	.453	.099	.469	.270	.015	.056	.273	.172	.314	.360	.402	.469	.003
	.16	.16	.16	.16	.16	.16	.16	.16	.16	.16	.16	.16	.16	.16

** . Correlation is significant at the 0.01 level (2-tailed). * Correlation is significant at the 0.05 level (2-tailed)

Appendix G: Interview Schedule: Cancer Patients

Communications

How would you describe the communication you had with medical professions during your illness?

How would you describe the communication you had with family and friends during your illness?

Support

What kinds of support services, if any, were you offered?

If yes, when was this offered?

If yes, who provided this information (Doctor, Nurse, other health care professional)?

What was the nature of the support offered?

Were you satisfied with this support?

Who do you think should be responsible for offering this support (e.g., Oncologist, GP, Nurse, other)

Treatment

How about your treatment, do you think things could've been done differently?

Were you satisfied with the treatment options provided to you?

Were you happy with the information provided to you about treatment options and/or the consequences of treatment

Did you notice any unusual symptoms (i.e. things not told about) following treatment?

For instance, did you notice any differences in your memory or thinking ability?

Expectations

In terms of your experience with your Doctors, were your expectations met?

If yes, How?

If no, what were your needs?

How do you think these could be met?

Psychosocial/Emotional

1. Did you have an opportunity to express how you were feeling to anyone? (e.g, family/friends/doctors/counsellors)
2. If yes, how do you think this benefited you?
3. If no, would you have liked this opportunity?
4. Why do you think this would have helped?
5. Would you be willing to participate in a therapy that involves expressing your emotions concerning your illness (i.e. writing about your experiences with cancer)
6. The therapy will run for 1 hour per week for 8 weeks. Would this be ok?

Recommendations

1. In terms of developing recommendations for other people living with cancer do you think or feel that anything could have been done differently?
2. Do you think things could have been approached differently?
3. Could anything else have been done?
4. Do you have anything else do add?

Appendix H: Responders versus Non-Responders

Table 1: Means scores for Participants (N=10) versus Non-Participants (N=6)

	Groups	N	Mean	Std. Deviation
Age	1	10	55.10	9.12
	2	6	59.00	8.74
Physical wellbeing	1	10	22.10	4.45
	2	6	23.00	3.68
Social and family wellbeing	1	10	18.00	5.37
	2	6	16.33	5.15
Emotional wellbeing	1	10	19.50	2.12
	2	6	18.83	4.21
Functional wellbeing	1	10	20.10	5.10
	2	6	23.66	4.50
Spiritual wellbeing	1	10	29.80	4.36
	2	6	36.22	9.21
FACT-G	1	10	79.70	13.31
	2	6	81.83	8.58
DASS: Stress	1	10	7.50	6.77
	2	6	6.34	4.18
DASS: Anxiety	1	10	5.40	7.35
	2	6	2.55	1.45
DASS: Depression	1	10	6.20	9.06
	2	6	2.46	2.77
Religiousness Involvement	1	10	1.60	1.07
	2	6	2.16	1.83
Months since diagnosis	1	10	60.20	52.78
	2	6	45.33	22.48
IES-R Avoidance	1	10	8.90	4.79
	2	6	5.83	2.63
IES-R Intrusions	1	10	6.80	6.14
	2	6	5.80	3.90
IES-R Hyper-arousal	1	10	4.70	4.69
	2	6	2.50	3.56
IES-R – total	1	10	20.40	13.63
	2	6	14.14	8.69
Inhibition: Anger	1	10	21.20	2.25
	2	6	17.31	3.25
Inhibition: Anxiety	1	10	16.60	1.17

	2	6	16.36	1.23
Inhibition:	1	10	18.50	3.20
Depression	2	6	18.10	2.61
Emotional	1	10	19.60	6.32
processing	2	6	23.93	6.54
Emotional	1	10	16.10	6.00
expression	2	6	22.00	5.72
Anxious	1	10	22.10	5.56
Preoccupation	2	6	21.33	5.35
Helpless/Hopeless	1	10	8.40	2.36
	2	6	8.00	1.67
Fighting Spirit	1	8	54.12	3.52
	2	6	51.66	5.16
Fatalistic	1	9	15.88	1.90
	2	6	13.83	4.91
WAI: distress	1	10	28.32	11.37
	2	6	26.83	5.49
WAI: restraint	1	10	99.49	5.62
	2	6	97.32	8.68
LDM: Need for	1	10	38.94	4.68
Harmony	2	6	35.16	3.76
LDM;	1	10	36.40	4.14
Rationality/Emotion	2	6	36.50	2.73
al Defensiveness				

Appendix I: Materials for Study 5: Emotion Chart (chapter 8)

Primary Emotions	Emotion Labels
LOVE	Adoration Affection Love Fondness Liking Attraction Caring Tenderness Compassion Sentimentality Arousal Desire Lust Passion Infatuation Longing
JOY	Amusement Bliss Cheerfulness Gaiety Glee Jolliness Joviality Joy Delight Enjoyment Gladness Happiness Jubilation Elation Satisfaction Ecstasy Euphoria Enthusiasm Zeal Zest Thrill Exhilaration Contentment Pleasure Pride Triumph Eagerness Hope Optimism Enthrallment Rapture Relief
SURPRISE	Amazement Surprise Astonishment
ANGER	Aggravation Irritation Agitation Annoyance Grouchiness Grumpiness Exasperation Frustration Anger Rage Outrage Fury Wrath Hostility Ferocity Bitterness Hate Loathing Scorn Spite Vengefulness Dislike Resentment Disgust Revulsion Contempt Envy Jealousy Torment
SADNESS	Agony Suffering Hurt Anguish Depression Despair Hopelessness Gloom Glumness Sadness Unhappiness Grief Sorrow Woe Misery Melancholy Dismay Disappointment Displeasure Guilt Shame Regret Remorse Alienation Isolation Neglect Loneliness Rejection Homesickness Defeat Dejection Insecurity Embarrassment Humiliation Insult Pity Sympathy
FEAR	Alarm Shock Fear Fright Horror Terror Panic Hysteria Mortification Anxiety Nervousness Tenseness Uneasiness Apprehension Worry Distress Dread

Appendix J: Additional Data for Case Study (chapter 8)

Table 1. DASS subscale scores at baseline

	Baseline		
	Stress	Anxiety	Depression
1	19	15	28
2	4	0	1
3	2	0	4
4	5	0	0
5	2	0	0
6	0	0	0
7	18	20	15
8	9	10	9
9	12	7	4
10	4	2	1

Table 2. DASS scores, baseline to post-intervention

	Baseline	Time 1	Time 2	Time 3	Time 4	Post-Int
1	62	23	45	64		
2	5	27	34	21	20	12
3	6	15	8	4	10	1
4	5	8	20	8	6	1
5	2	2	9	0	10	0
6	0	12	1	0	11	10
7	53	29	35	31	19	29
8	28	26	9	99	17	20
9	23	49	33	19	6	22
10	7	9	7	14	6	3

Table 3. DASS subscale scores, baseline and post-intervention comparisons

	Baseline			Post-Intervention		
	Stress	Anxiety	Depression	Stress	Anxiety	Depression
1	19	15	28			
2	4	0	1	3	5	4
3	2	0	4	1	0	0
4	5	0	0	1	0	0
5	2	0	0	0	0	0
6	0	0	0	10	0	0
7	18	20	15	11	13	5
8	9	10	9	5	8	7
9	12	7	4	14	4	4
10	4	2	1	1	2	0

Table 4. CES anger, anxiety and depression, baseline and post-intervention

	Anger		Anxiety		Depression	
	Baseline	Post-Int	Baseline	Post-Int	Baseline	Post-Int
1	28		28		28	
2	18	14	16	14	17	17
3	25	16	13	12	23	13
4	19	27	19	14	18	17
5	22	15	19	24	16	15
6	24	19	19	20	22	18
7	21	19	15	15	14	16
8	25	22	23	21	22	20
9	19	16	20	18	21	16
10	23	21	20	22	20	22

Table 5. EAC subscales, baseline and post-intervention

	Emotional Expression		Emotional Processing	
	Baseline	Post-Int	Baseline	Post-Int
1	27		28	
2	16	12	15	14
3	12	21	26	28
4	16	16	22	25
5	8	11	9	11
6	11	14	16	13
7	21	21	24	27
8	16	18	20	25
9	23	16	24	24
10	11	9	12	9

Table 6. FACT-G subscale scores, baseline and post-intervention

	Physical		Social/Family		Emotional		Functional	
	Baseline	Post-Int	Baseline	Post-Int	Baseline	Post-Int	Baseline	Post-Int
1	13		23		18		12	
2	21	20	21	18	19	18	22	22
3	20	21	14	20	19	22	14	23
4	27	27	23	21	21	24	26	28
5	23	18	19	20	22	23	25	20
6	27	27	17	14	23	21	27	25
7	22	20	7	26	17	18	18	20
8	23	23	19	22	17	18	18	21
9	18	22	13	11	18	19	17	18
10	27	27	24	20	21	20	22	23

Table 7. Avoidance, intrusions and hyper-arousal subscales pre and post-intervention.

	Avoidance		Intrusions		Hyper-arousal	
	Before	After	Before	After	Before	After
1	12		5		9	
2	10	9	12	9	4	5
3	2	1	2	0	1	0
4	2	10	0	3	0	1
5	11	17	3	0	1	0
6	14	11	4	8	1	2
7	12	8	19	19	11	9
8	9	7	11	12	5	2
9	14	12	11	10	13	7
10	3	7	1	12	2	4

Table 8. STPI, anger, curiosity, anxiety and depression: baseline and post-intervention

	Anger		Curiosity		Anxiety		Depression	
	Baseline	Post-Int	Baseline	Post-Int	Baseline	Post-Int	Baseline	Post-Int
1	10		26		23		25	
2	10	11	34	28	12	19	12	16
3	12	10	32	32	14	17	16	17
4	10	10	39	39	10	18	10	16
5	10	10	19	17	16	16	16	18
6	10	10	30	27	11	16	11	17
7	15	10	26	31	31	21	34	24
8	10	10	24	30	19	21	19.4	19
9	19	14	29	26	23	19	21	18
10	10	10	24	23	15	17	17	17

Table 9. Emotion labels used throughout the intervention

Patient Number	Week 1: Diagnosis		Week 2: Treatment		Week 3: Awaiting Results/Visits with Specialists		Week 4: Remission	
	<i>Positive Emotions</i>	<i>Negative Emotions</i>	<i>Positive Emotions</i>	<i>Negative Emotions</i>	<i>Positive Emotions</i>	<i>Negative Emotions</i>	<i>Positive Emotions</i>	<i>Negative Emotions</i>
1	1	4	1	3	3	7	n/a	n/a
2	1	0	2	1	1	2	2	3
3	4	18	4	9	5	7	11	11
4	8	6	6	8	12	16	14	6
5	0	10	5	6	0	4	2	2
6	2	9	2	5	2	5	1	1
7	1	3	1	5	3	7	0	4
8	0	7	4	3	2	5	1	4
9	1	11	3	5	6	21	2	9
10	0	3	1	2	1	4	2	0

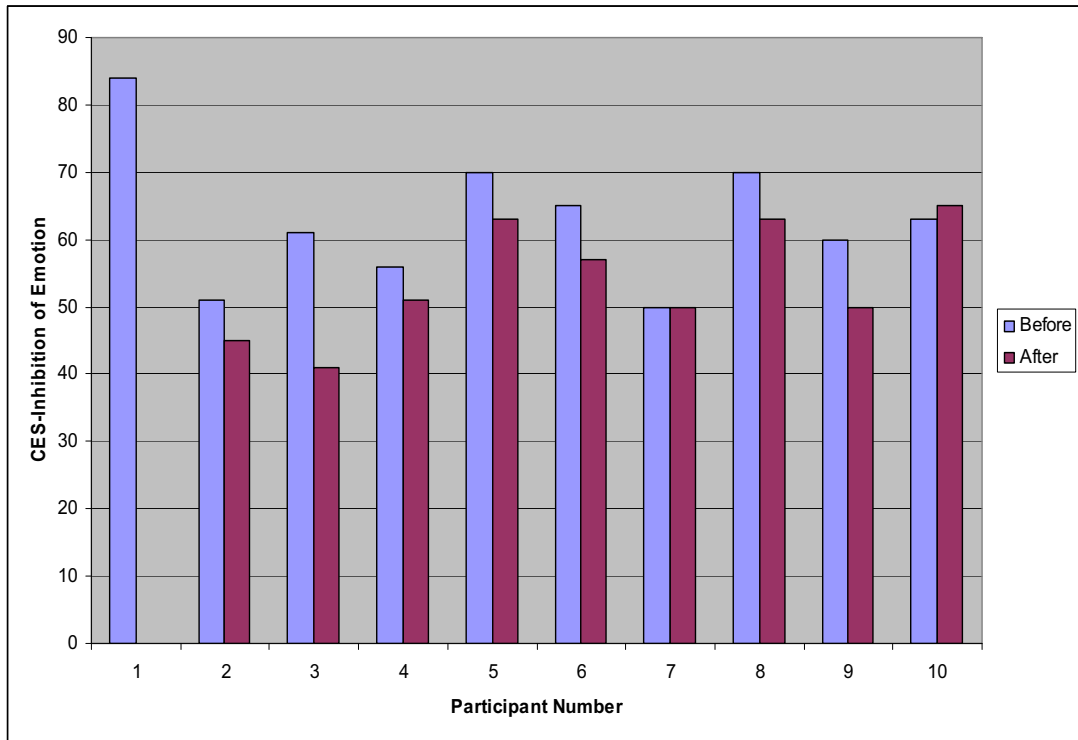


Figure 1. CES, inhibition, baseline-post intervention

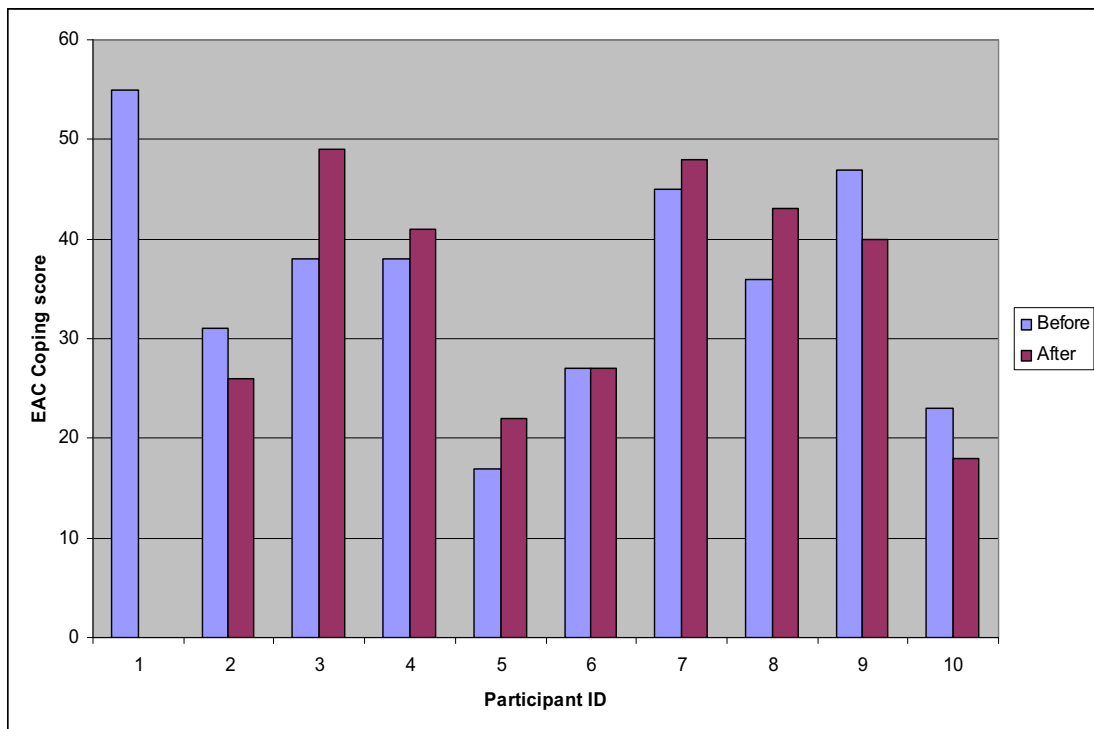


Figure 2. EAC coping, baseline-post intervention

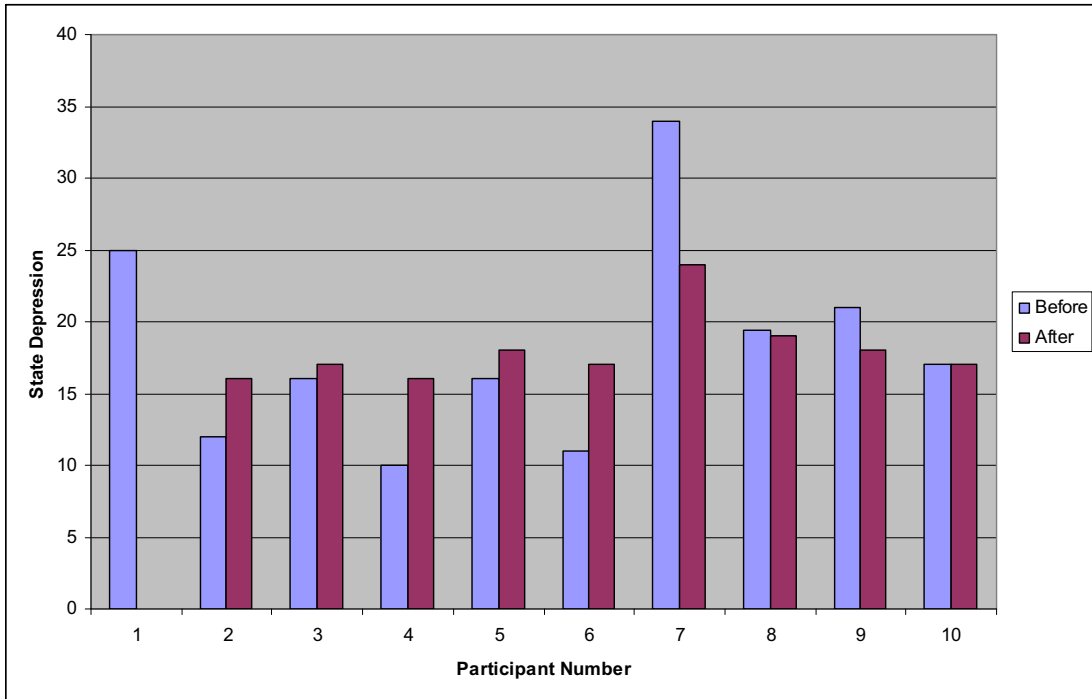


Figure 3. STPI depression, baseline and post-intervention

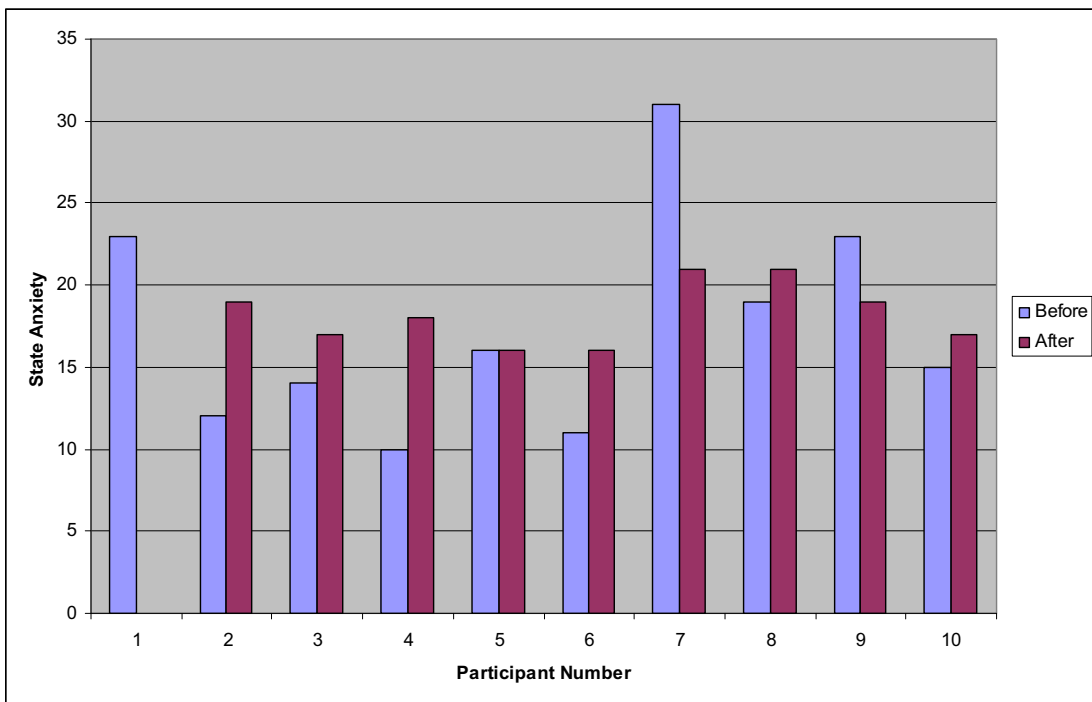


Figure 4. STPI anxiety, baseline and post-intervention

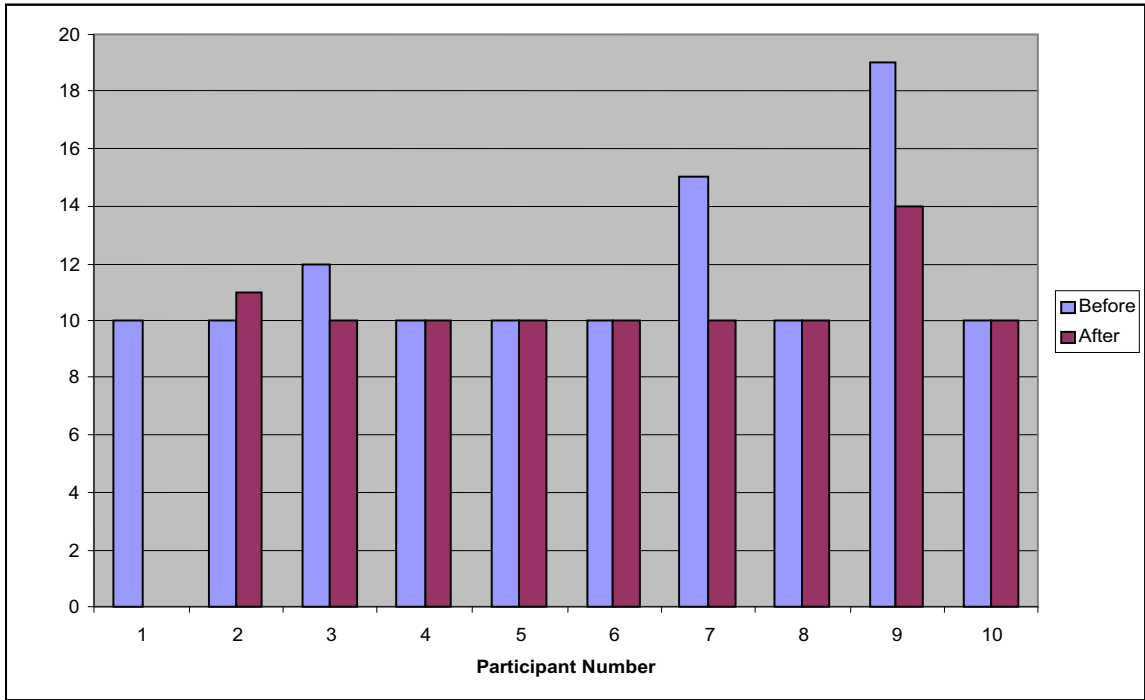


Figure 5. STPI anger, baseline and post-intervention.

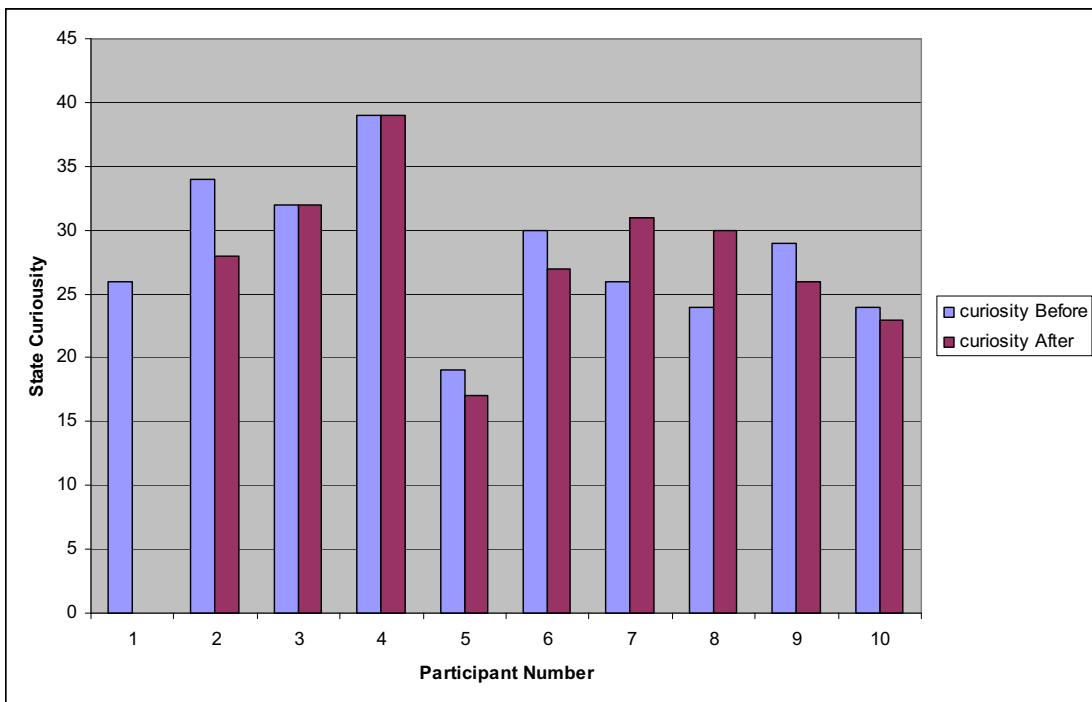


Figure 6. STPI curiosity, baseline and post-intervention

Appendix K: Interview Schedule: IBS Patients

INTERVIEW SCHEDULE

Version 4

Warm up: Introduce self and explain purpose of study (as per information sheet), go through participant requirements and have participant sign informed consent.

Ok, so I would like to ask you some questions about your appointment with the gastroenterologist specialist.

Most of the questions I ask you focus on the kinds of expectations you may, or may not have had prior to meeting with the gastroenterologist today.

Other questions focus on your general satisfaction with the consultation today.

Now, please remember that all the information you supply is strictly confidential and nothing you say will not be linked with your name. So in other words please feel free to be open and honest in anything you might want to say.

1. How did you come to be referred here today?
2. So, how was your appointment today? Note responses and Probe for elaboration (Q1a, Q1b, Q1c, Q1d, Q1e).
 - a. What did you hope the specialist would do for you today?
 - b. To what extent do you feel he/she was able to do this?
 - c. What did you hope to get from your specialist appointment today?
 - d. Did this happen (i.e. did it meet with your expectations)?
 - e. Was there something in particular that you expected to happen today?
 - f. Was there something in particular that you hoped to get from your appointment today?
 - g. Thinking back now, prior to meeting with the specialist, were there any particular questions you wanted answered today, (wait)..... or perhaps there were certain issues you wanted addressed ?
 - h. Put another way, did you come to your appointment today expecting that certain things would happen?
 - i. Did this happen?
 - j. Were you disappointed by this? (wait)..... Why do you think this should've happened?
3. How long have you waited for your appointment?
4. Were you been given a diagnosis today?
 - a. Were you surprised by this diagnosis?
 - b. Is this a diagnosis you've been given before?
 - c. To what extent would you say that you are "happy" or "agreeable" with this diagnosis?

13. Could you give me a brief overview of different health practitioners you've seen for your symptoms.
 - a. In terms of the services accessed would you say that you were satisfied with these services?
14. Prior to your appointment today, did you know what was wrong with your Gut?
15. What is it that most bothers you about your Gut symptoms?
16. What do you think causes your symptoms?
17. What does your specialist think causes your symptoms?
18. Have you seen other specialists for these symptoms?
 - a. If yes, what happened on this occasion?
 - b. Why are you seeing another specialist? OR
 - c. What is it that makes you see someone at this point in time? (wait). For instance, did someone in particular recommend that you be referred here today?
19. What did your GP (if specialist, note specialist) tell you would happen today?
 - a. Did this happen?
 - b. To the best of your knowledge, do you think the specialist was given an adequate and/or accurate account of your symptoms?
 - c. To the best of your knowledge, do you think the specialist was made aware of all issues relevant to your illness?
 - d. To the best of your knowledge, do you think the specialist was given an adequate and/or accurate account of tests you've already had completed?
20. Prior to today, could you give me an overview of the kinds of tests you've had done?
21. Did your specialist order any tests today?
22. Did you expect that he/she would order further tests?
23. Have you received any treatment, or tried anything different (e.g. dietary changes) for these gut symptoms?
24. Were any of these helpful to you?
25. Have you ever visited an alternative therapists for your symptoms? If yes, was this effective?
26. Do you think having these symptoms affects your quality of life?
 - a. If yes, in what way?
27. In terms of impacting on your day to day living, and on a scale of 1 (not at all) to say 4 (moderate), and 7 (severe impact) to what extent do these symptoms impact on your life

1 _____ 4 _____ 7

not at all

moderate

severe impact

28. Is there a particular area of your life where this impact is greater? (i.e. home, work, social)

29. On a scale of 1 (mild) to 7 (severe), how severe would you rate the severity (in terms of pain) of your symptoms

1 _____ 7
mild severe

30. In s there anything you can think of that could be done to help you manage your symptoms

31. Is there anything you can think of that could be done to reduce the impact that these symptoms have in terms of your general day to day life

32. In terms of improving the consultation today, do you have any recommendations about how things could be improved?

33. Looking ahead, say towards say a year from now, where do you hope to be with this condition

Give questionnaire and advice to send back in return paid envelope, and just note the following information

1. ID:
2. Age:
3. Gender:
4. DOB:
5. Occupation:
6. Other Chronic Conditions
7. Any Psychological conditions
8. Where Born
9. When first received diagnosis

Appendix L: Intercorrelations study variables(IBS study, Chapter 9)

Table 1: Intercorrelations Health Care Use variables

		Concerns Addressed	Satisfaction with Appointment	Impact on Quality of Life	Severity of Pain	Services Accessed	Number of specialists seen	Number of tests/procedures
Concerns Addressed	Pearson Correlation	1						
	Sig. (2-tailed)							
	N	21						
Satisfaction with Appointment	Pearson Correlation	.704**						
	Sig. (2-tailed)	.000						
	N	21						
Impact on Quality of Life	Pearson Correlation	-.159	-.095					
	Sig. (2-tailed)	.490	.682					
	N	21	21					
Severity of Pain	Pearson Correlation	-.185	-.200	.352				
	Sig. (2-tailed)	.421	.384	.118				
	N	21	21	21				
Services Accessed	Pearson Correlation	-.445*	-.271	.610**	.528*			
	Sig. (2-tailed)	.043	.234	.003	.014			
	N	21	21	21	21			
Number of specialists seen	Pearson Correlation	.105	.160	.337	.161	.471*		
	Sig. (2-tailed)	.649	.488	.135	.485	.031		
	N	21	21	21	21	21		
Number of tests/procedures	Pearson Correlation	-.128	-.235	.041	.154	.347	.230	
	Sig. (2-tailed)	.581	.306	.858	.505	.124	.317	
	N	21	21	21	21	21	21	
Number of times seen current specialist	Pearson Correlation	-.220	-.069	.041	-.119	-.061	-.257	.252
	Sig. (2-tailed)	.337	.766	.859	.606	.792	.261	.270
	N	21	21	21	21	21	21	21

** . Correlation is significant at the 0.01 level (2-tailed). * Correlation is significant at the 0.05 level (2-tailed)

Appendix M: Presentations based on the work presented in this thesis

Accepted oral presentations for 2008

1. Knott, V., Turnbull, D., Olver, I., & Winefield, A. (2008, June). Helping patients cope with cancer. *Sydney Cancer Conference (July)*.
2. Knott, V., Andrews, J., Turnbull, D. & Holtmann, G. (2008, August). IBS and outpatient services: Towards the development of an empirical model of health care utilization. *International Congress of Behavioural Medicine, Toyko, (August)*.
3. Knott, V., Andrews, J., Turnbull, D. & Holtmann, G. (2008, August). Satisfaction of IBS patients with medical consultations: Role of patients' expectations. *International Congress of Behaviour Medicine, Toyko*.

Accepted poster presentations for 2008

4. Knott, V., Andrews, J., Turnbull, D. & Holtmann, G. (2008, August). IBS and outpatient services: Towards the development of an empirical model of health care utilization. *Digestive Disease Week, Sandiago (May)*.
5. Knott, V., Turnbull, D., Olver, I., Winefield, A., & Smith C. (2008, August). *Can the expression of negative emotion be therapeutic for cancer patients? 10th International Congress of Behavioural Medicine, Tokyo*.
6. Knott, V., Turnbull, D., Olver, I., Winefield, A., & Smith C. (2008, August). *Exploring the psychosocial needs of cancer patients. 10th International Congress of Behavioural Medicine, Toyko*.

Invited Seminars for 2008

7. Knott, V. (2008). Helping patients cope with cancer. *School of Psychology Colloquium: The University of South Australia*.

Published Abstracts

8. Knott, V., Andrews, J., Turnbull, D. & Holtmann, G. (2007). IBS and outpatient services: Towards the development of an empirical model of health care utilization. *Journal of Hepatology and Gastroenterology, 22 (Suppl 3), A284*.
9. Knott, V., Andrews, J., Turnbull, D. & Holtmann, G. (2007). Satisfaction of IBS patients with medical consultations: Role of patients' expectations. *Journal of Hepatology and Gastroenterology, 22 (Suppl 3), A290*.

Oral Presentations

10. Knott, V., Winefield, A., Turnbull, D. Olver, I., Smith, C., & Blake-Mortimer, J. (2006, June). *Stress, emotional inhibition and cancer: Implications for intervention and assessment of treatment efficacy*. Paper presented at the 27th Stress & Anxiety Research Society Conference, Rethymnon, Crete, Greece.
11. Knott, V., Andrews, J., Turnbull, D. & Holtmann, G. (2007, October). *Satisfaction of IBS patients with medical consultations: Role of patients' expectations*. Paper presented at Australian Gastroenterology Week (Perth).

Poster Presentations

12. Knott, V., Andrews, J., Turnbull, D. & Holtmann, G. (2007, October). IBS and outpatient services: *Towards the development of an empirical model of health care utilization*. Australian Gastroenterology Week (Perth).
13. Knott, V., Andrews, J., Turnbull, D. & Holtmann, G. (2007, October). *Towards the development of an empirical model of health care utilisation*. University of Adelaide, Student Research Forum.
14. Knott, V., Andrews, J., Turnbull, D. & Holtmann, G. (2007, October). *Satisfaction of IBS patients with medical consultations: Role of patients' expectations*. University of Adelaide, Student Research Forum.
15. Knott, V., Turnbull, D., Olver, I., Winefield, A., & Smith C. (2007, October). *Can the expression of negative emotion be therapeutic for cancer patients?* University of Adelaide, Student Research Forum.
16. Knott, V., Turnbull, D., Olver, I., Winefield, A., & Smith C. (2007, October). *Exploring the psychosocial needs of cancer patients*. University of Adelaide, Student Research Forum.