

DIFFERENTIATION OF PSYCHOSOCIAL ISSUES BETWEEN CHRONIC ILLNESS GROUPS: DEVELOPMENT OF A SCALE

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ABSTRACT

The aim of this thesis was to develop a scale to measure psychosocial status of people with chronic illness, resulting in an overall measure of attitude to life post diagnosis, to gauge a measure of physical mobility, and to determine differences and similarities in areas of concern and need, across three diagnostic groups: diabetes, arthritis and stroke. The Theory of Reasoned Action (Ajzen & Fishbein, 1980) and the research process described by Fishbein and Ajzen, underpinned the development of the scale. The first stage of the study determined the beliefs and people (salient beliefs and normative referents) which were most important to the individual in relation to their illness. Sixty-two people were interviewed. Analysis of their responses identified 18 salient beliefs and 6 normative referents, which then formed the basis of items, pertaining to attitude to life and social/normative referents, on the scale developed in stage two. Stage 2 piloted a questionnaire comprising this 48-item scale, a measure of mobility scale and demographic details. Results showed that the scale discriminated between the three diagnostic groups and correctly classified 98.6% of cases. It also showed significant differences in attitude to life across levels of mobility, with increased mobility related to more positive attitude. For the third stage, participants responded to a questionnaire incorporating the

attitude to life scale, the social referent scale and the mobility scale. In addition, the Wallston Health Locus of Control Scale was included to provide a measure of validity. As expected, the Attitude to Life Scale was negatively correlated with internal locus of control and positively correlated to external locus of control. Results showed the scale correctly classified 79.4% of cases, showed good reliability, and good validity. Findings demonstrate that the scale identifies psychosocial needs of patients, and allows for comparisons between diagnostic groups. The discriminatory capabilities of the scale will allow better development and targeting of intervention programs for each diagnostic group.

DEDICATION

To my children, Shana and Kyle Evers, who gave *me* a sense of self
when *my* identity was threatened.

To my grandfather in whose name I submit,
and my grandmother, the strongest woman I ever knew.

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CHAPTER 1

INTRODUCTION

Chronic illness is permanently affecting, perpetual and disruptive (Weisman, 2001), unlike an acute illness, which quickly reaches a crisis, requires immediate intervention, and is then resolved. The impacts of chronic illness are diverse and all encompassing. Patients are faced with incurable illnesses with varying levels of debilitation, and potential for physical disability, disfigurement and, possibly, shortened life expectancy (Gregg, Robertus, & Stone, 1989).

Society and Chronic Illness

As our population ages, chronic illness is increasingly a concern in terms of cost to health programs, cost to governments, costs to society at large, utilisation patterns of hospital facilities, and provision of appropriate services. Chronic illness is the most prevalent health concern in western societies, and poses "one of the greatest challenges facing health care professionals today" (McRae & Smith, 1998). This was recognised as early as three decades ago when Cole (1974) noted that 50% of the population required medical treatment for a chronic illness at any one time. DeBusk, West, Miller and Taylor (1999) emphasised that "the needs posed by patients with chronic disease are overwhelming the American Health Care

system” (p. 2739). They noted the \$600 billion cost, which was attributable to the treatment of chronic diseases in 1990, but point to further escalation in costs as the population ages. Despite such expenditure, the Health Care systems are seen as inadequately addressing the needs of people with chronic illnesses, by neglecting to address “the presence of social and psychological impediments” (p. 2739).

Research, which specifically examined the cost of treatment of chronic illness, has examined this issue in relation to children. Silber, Gleeson and Zhao (1999) reported that mean hospital charges were \$1049 higher for patients with at least one chronic illness than for patients without chronic illnesses. This figure more than doubled for patients with two or more chronic illnesses. This type of research, coupled with statistics showing an aging population and correlated increased incidence of chronic illness, highlights an urgent need to better understand chronic illness in adults.

In Australia, scant research attention has addressed the issue of the growing burden of chronic illness. One of the first studies to examine this (Mathers, Vos, Stevenson & Begg, 2001), adopted methodology developed for the Global Burden of Disease Study. This study explored the burden of disease in terms of years of life lost to disability (YLD), but noted the uncertainty of this calculation in relation to illnesses with long-term sequelae. They did, however, emphasise the importance of such research in

Australia: facing issues of “an aging population... and increasing costs to health services” (p. 1088). The Australian department of Health and Aging (1999) reported that, in 1998, 12% of Australia’s population was aged over 65 years. They estimate that this will rise to 18% by 2021 and to 26% by 2051. The estimated percentage of population over 65 years was nine percent in 1976 and is projected to rise to 25% in 2041. Furthermore, of those over 65 years of age, one in six were aged 80 and over in 1976, one in five in 1996, and estimates project it will be one in four by 2016, and one in three by 2041.

Compounding the portent of these figures are estimates that around three million Australians had a chronic illness in 2000 (Wooldridge, 2000). It is no surprise then, that Wooldridge spoke of chronic illnesses as “one of the greatest challenges for Australia and, indeed, the world in the 21st century” (p. 1).

Those diagnosed with chronic illness usually cannot expect to regain their health in the near future, and face a certain amount of ongoing despair and depression in response to the experience of chronic illness (Powell, 1998). Despite this, recognition of the impact of chronic illness on people's lives has been slow to emerge (Atkinson, 1993; Dimond & Jones, 1983).

Psychosocial Stress of Chronic Illness

Chronic illness is lifelong and has no cure. It requires adjustment to the demands of the illness, the many and varied symptoms, and to the

therapy used to treat the illness. Additional stresses may arise, since chronic illness might change the way a person lives, sees themselves and relates to others.

Several potential causes for concern and stress have been identified in people with a chronic illness. Kohler, Schweikert-Stary, and Lubkin (1990) suggested that other psycho-social effects of chronic illness include loss, self-image, isolation, fear, travel, stress, family, role changes, sexual functioning and aging. They suggested that societal barriers to the chronically ill include the attitudes of others toward the ill person, stigma, and language use, environmental and architectural barriers, and transport. When viewed in a disease specific fashion, similar cause for concern has been identified. Kettle and Chamberlain (1989), studying the issues regarding stroke, identified loss of mobility, transport problems associated with not driving a car, relying on other people, limited leisure time activities and depression. In regard to rheumatoid arthritis, Krol, Sanderman and Suurmeijer (1992) identified areas of concern around a loss of independence, social withdrawal, loss of employment, reduced leisure activities, and financial problems. Similarly, Hess, Davis & Harrison (1987) identified issues for diabetes patients as including adherence to the treatment regimen, issues of control, problems with relationships, financial concerns, and reduced abilities to work, travel and be active. Thus, it is plausible to suggest that people with chronic illness deal not only with a

varied array of symptoms and medical treatments, but also with the detriments imposed as a result of the psycho-social adjustment associated with coping with the illness.

Adjustment to illness is determined by a variety of factors including: premorbid personality, body image, attitude of care givers, self concept, emotional resources, marriage and family relationships, social adjustment, career adjustment and planning, and recreational and leisure activities (Safilios-Rothschild, 1970; cited in Gregg, Robertus, & Stone, 1989, p. 7). Complicating this is the tendency for social devaluation of people who are chronically ill (Goffman, 1963).

Psychosocial adjustment is strongly associated with salient role behaviours. For example, vocational, social-leisure time, and domestic (Derogatis, 1986), with each being threatened by the somatic and emotional effects of chronic illness. These social roles may require concomitant modification (Brooks & Matson, 1982), as individuals are unable to fulfil roles in the previous way or unable to fulfil them at all.

Compounding the issues faced by individuals with chronic illness is the impact such illness has on the families of patients, as family structure, roles, financial situation, and social activities necessarily change in response to the demands of coping with chronic illness. Because of the physical changes that occur, loss of income due to job restriction, or the need for help from other, family and friends are often affected by one individual's

experience of chronic illness (Turk & Kerns, 1985). A patient's spouse may suddenly have to take on additional responsibilities that once fell onto the partner who is now ill. Young children must sometimes assume responsibilities than would not normally be expected for their age group. Often then, it is not only the patient who may experience psychosocial difficulties, but also the spouse, children and others who must adjust to these changes (Coyne & Smith, 1991).

These changes in roles and associated behaviours and expectations are further confounded when physical mobility becomes an issue. Several studies (e.g., Pollock, Christian & Sands, 1990; Russell, 1989; Westbrook & Viney, 1982) of psychological adjustment to chronic illness have found that the level of perceived disability was central to the perception of the overall health attitude. Similarly, in developing and incorporating a measure of mobility, Evers and Karnilowicz (1996), similarly, found that physical disability had a strong impact on overall attitude to life.

Traditionally, chronic illness has been conceptualised in terms of a disease-centred biomedical model utilising biotechnical intervention to remove causative factors (Dimond & Jones, 1983; McWilliam, Stewart, Brown, Desai & Coderre, 1996). Research within the psychological domain has also tended to focus on specific diagnoses, rather than on the similarities or differences in adaptation to various chronic illnesses (Pollock, Christian, & Sands, 1990). However, in recent years, a biopsychosocial perspective on

illness has emerged (Dimond & Jones, 1983; Taylor & Aspinwall, 1990).

This model considers the interplay of biological, psychological and social aspects of the person's life.

Much research continues with regard to cause and cure of illness.

Meanwhile, many individuals are faced with the daily changes such illness makes to their lives. Further knowledge is needed about human responses to chronic illnesses in order to plan appropriate intervention studies that enhance adaptive responses (Pollock, 1986; Pollock, Christian, & Sands, 1990).

Motivation for the Present Study

The aim of this thesis was to develop a scale to measure psychosocial status of people with chronic illness, and provide a means for busy medical centres to identify a starting point in appropriately meeting patients' individual needs. Moreover, such a scale, resulting in an overall measure of attitude to life post diagnosis and a measure of physical mobility, allows identification of differences and similarities in areas of concern and need, across diagnostic groups. Potentially, this enables efficient development of services to meet the unique needs of patients with particular diagnoses while simultaneously allowing for appropriate joint utilisation of services across diagnostic groups.

A secondary purpose of this study was to extend previous research and to generalise the understanding to a broader sample of patients with

chronic illness. Experience with people with Multiple Sclerosis focussed awareness of their needs, in dealing with illness-related issues and changes to their psychological and social well-being, as well as the potentially negative changes to self-concept. Several questions arise from the MS research. Are people experiencing other chronic illnesses, coping with the same problems experienced by those with MS, or are there specific and differing issues for different disease groups? Are there different issues for people at different stages, or with different forms of each disease?

In order to answer some of these questions the research will examine disease groups, which are similar in terms of chronicity and adult onset - these include stroke, arthritis, and diabetes. Issues of mobility are likely to vary over the illnesses. By including the potential for variation on this domain, the effect of impaired or altered physical mobility can also be investigated. The issue at hand is broadly one of coping and attitude and manifests as the psychological and psychosocial sequelae of chronic illness.

Perspective of This Study

The proposed research will be relatively stronger in that the perspective for the research, and the basis for the final scale will be derived from the input of patients, but is also bound into theories that have been used to inform this area before. Several social psychology theories indicate that attitudes and beliefs (about disease, body and image) are all important elements in adjustment (e.g., Stress, Appraisal and Coping, Lazarus &

Folkman, 1984; Theory of Reasoned Action, Ajzen & Fishbein, 1980). Furthermore, the methodological shortcomings of previous research (e.g., small sample size, poor representativeness, limited scope of variables, not based on identified salient issues) will be addressed.

Previous research tends to be fragmented in that each piece of research deals specifically within a very limited focus. Thus, the disease and persons with the disease are not dealt with as a whole: persons with the disease are not treated as one whole person, but as a manifestation of the disease. Therefore, the overall psychosocial impacts of the disease, the psychosocial consequences of the disease, and the psychosocial needs of persons with the disease are not clearly identified. Moreover, previous research has used disease-specific instruments. While these have been shown to be useful, reliable and valid, they do not enable comparisons across disease groups. Consequently, without comparisons, appropriate application of different interventions is not possible. The current research proposes to use an instrument, for comparative purposes, which can be applied across the selected disease groups.

Successful management of chronic diseases depends largely on patients' ability to cope with the diagnosis, the physical, psychological and social ramifications of the disease, and with the ongoing disease management regimes. Identifying issues, which impede adjustment and coping, is paramount to the psychosocial well-being of the patient, families,

and to the course of the disease as it is effected by disease management. However, within the constraints of the hospital system in particular and the medical system at large, which is confined by staff shortages and limited funding, access to psychologically trained professional which would allow patients to explore and identify their psychosocial needs, is largely impossible. Thus, a reliable and valid instrument which can be administered relatively easily and quickly, or which could be self-administered, is potentially invaluable to patients struggling to verbalise their experience and to practitioners trying to optimise treatment outcomes.

Brief Summary of Project Significance

This research addresses the needs of patients with chronic disease, as well as identifying areas for appropriate development of services. In identifying the psychological and social concerns and needs of those with chronic illness, it is inevitable that some of the concerns, which impact negatively on family members and family structure, will be identified.

These areas must be identified and addressed in order to enhance the quality of life of these individuals, as well as their families. The repercussions for society are mammoth. The outcomes of research such as that proposed, resulting in the identification of salient issues and needs of these persons, will result ultimately in those individuals making less demands on our already over-stretched health care system, and in these

individuals being able to continue to contribute to society in ways which are meaningful for themselves and for broader society.

Overall Aims

- 1 To assess psychological and social areas of concern and need for persons with chronic illness, as represented by the three diagnostic groups of interest.
- 2 To gauge a measure of physical mobility.
3. To develop a questionnaire to measure the psychosocial status of persons with chronic illness, resulting in an overall measure of attitude to life.

Overall Hypotheses

1. Because of the experience of chronic illness there will be behavioural and normative beliefs that are found to be consistently salient across all the disease groups.
2. There will be differences between the illness groups in regard to specific behavioural and normative beliefs.
3. There will be variation in overall measure of attitude to life dependent on the gauged level of mobility, with higher levels of mobility being related to more positive attitude.
4. As the use of *visible* mobility aids (walking stick, frame, wheelchair) increases, the measure of attitude to life will become more negative.

5. As driving a car increases, the measure of attitude to life will become more positive.

Thesis Outline

The present research examines the psychosocial aspects of chronic illness, where 'psycho-social' is defined as the individual's perception of well-being with respect to the daily mien of social and emotional life. Three chronic illness groups were represented; Type II diabetes, rheumatoid arthritis and non-aphasic stroke.

Arthritis consists of 150 forms ranging from mild to severe symptoms, the most common being persistent pain, swelling or stiffness in one or more joints. In its severest form, arthritis may cause gross deformity of joints and result in total lack of use of effected areas, causing inability to write, dress or walk (Arthritis Foundation of Victoria, 1997).

Diabetes is a collection of conditions characterised by impaired glucose metabolism (Gregg, Robertus & Stone, 1989). Type I diabetes is the least common form, affecting 10-15% of all cases, usually diagnosed during childhood, and treated with insulin. Type II diabetes is the most common form, representing 85-90% of all cases, usually occurring in people over the age of 30. It is usually treated by changes in, and constant monitoring of, diet and exercise. Type II diabetes can cause long term complications such as serious damage to the eyes, kidneys, nerves and blood vessels. Thus, it is the biggest cause of non-traumatic blindness and amputation.

Stroke is a condition in which damage to the brain occurs as a result of disruption to blood supply. Stroke or cardiovascular accident causes subtle to severe behavioural, intellectual and memory changes (Kolb & Whishaw, 1996). The most common deficits after stroke are paralysis, such as being unable to move one side of the body, resulting in inability to walk, dress or manage usual daily activities, impaired cognitive functioning, such as being unable to process language, to read or write, and emotional disorders, such as being unable to interpret or react to emotions.

Chapter Two provides the theoretical framework within which this thesis sits. Selected theoretical perspectives relating to self are presented. These are discussed in relation to chronic illness. Issues of physical mobility are used to highlight the application of each of the theories to understanding chronic illness. This chapter argues that chronic illness potentially underlies changes in self-concept and subsequent changes in self-esteem (Walsh & Walsh, 1987) and that this is reflected in the measure of attitude to life. Mobility is viewed from a symbolic interactionist approach, which argues that the use of visible mobility aids impact on the individual's attitude to life through a process of stigmatisation.

In order to move from a theoretical to an applied perspective, Chapter Three reviews the literature relating to chronic illness research. Since the link between theoretical perspectives and clinical research is not always apparent, the literature is examined in the categories of coping and

adjustment, and quality of life, within the broad framework of chronic illness. Mobility/disability as addressed specifically in the literature is also reviewed. This chapter then examines the literature concerning each of the diseases of interest: diabetes, arthritis, stroke. Ultimately it highlights the need for a different approach to research in chronic illness, arguing for a methodology which is non-disease specific and which provides for a patients' perspective.

Chapter Four establishes the relevant theoretical perspectives of the Theory of Reasoned Action (Ajzen & Fishbein, 1980) and explains the research process. Chapters Five, Six and Seven report on the research process conducted, and the findings obtained in each stage. An overview of the final results from the entire sample is contained in Chapter Eight. Finally, Chapter Nine reflects on the meaning of the results in light of the overarching aims of the research, with particular emphasis on practical implications and further applications.

CHAPTER 2

SELF AND CHANGES TO SELF

This thesis contends that the theoretical explanations of behaviour and attitude, which apply to people in general, are still applicable, when examining psychosocial adjustment among people with chronic illness. This is because, especially in cases of chronicity, the illness or condition and its symptoms cannot be the most salient, distinguishing feature of that individual's subsequent behaviour, experience and attitude. Rather, the chronic illness and its associated issues are incorporated in a dynamic process, and the relevance of issues concerning the illness, changes in concert with changes related both to the illness and to everyday life. Thus, ultimately, the personality dispositions, the social-cognitive beliefs, self-concept, learning experiences and environment of the individual are still relevant and important in shaping everyday experience. However, they are, in turn, shaped by the individual's experience of the chronic illness.

Although this research will ultimately focus on specific theoretical areas bearing on mobility and attitude, it is important to briefly discuss some of the broader theoretical areas that influence the study. These include locus of control, self-concept, self-esteem, self-discrepancy, and threats to self-identity. Each of these theoretical issues is relevant, particularly in relation

to mobility, and their relationship to chronic illness. Mobility (variously operationalised and named mobility, disability etc) has been shown to be a factor affecting a person's adaptation to chronic illness. The issue of mobility will be used to exemplify the ways in which each of the theoretical perspectives can explain the individual's response to chronic illness. Broadly speaking, this chapter will move from a behavioural to a cognitive perspective, and finally to the perspective of social interactionism.

Locus of Control

Locus of control refers to the degree to which individuals perceive themselves as being in control of the events in their life (Rotter, 1966). An external locus of control is the belief that outcomes are not determined by an individual's personal effort. Conversely, an internal locus of control is the belief that outcomes are contingent upon personal exertion. An individual is described as having expectations that are predominantly 'internal' or 'external' with regard to the causation and, subsequently, to control over outcomes.

Interest in the concept of control crystallised as focus on the construct originally defined as "a generalised expectancy [which] distributes individuals according to the degree to which they accept personal responsibility for what happens to them, in contrast to the attribution of responsibility to forces outside their control (chance, fate an ability to understand the world, or the influence of other powerful people)", (Battle &

Rotter, 1963, p. 482). Rotter continued to investigate this area and the assumptions that follow from application of this theoretical perspective, extending construct validity by demonstrating a significant interaction between internal-external control and skill versus chance instructions (1965, 1966). In reviewing a number of studies (1971), Rotter was able to apply the theory to offer an explanation of changes in society such as college protests, which he attributed to frustration associated with lack of control. As the construct became more widely used, Rotter identified conceptual and methodological problems, endeavouring to clarify the place of internal-external locus of control within social learning theory (1975). It is the ongoing work of Rotter (1990, 1992), which continues to validate and clarify the concept of Locus of Control and make it a useful perspective from which to gain understanding of human behaviour.

Early research revealed that an external locus of control was associated with a number of negative outcomes such as depression (Abramowitz, 1969; Naditch, et al., 1975), anxiety (Feather, 1967; Watson, 1967), and with being less able to cope with stressful experiences (Kobasa, 1979; Lefcourt, 1983, Sandler & Lakey, 1982). An internal locus of control was found to be associated with a more active pursuit of goals (Levenson, 1974; Sherman, 1973) and with a sense of wellbeing (Lefcourt, 1982). Thus, it can be expected that people whose locus of control in regard to their health is predominantly internal, would take more active personal

responsibility for their personal health outcomes and would, therefore, practice behaviours that enhanced their health status, for example, changing diet, getting checkups (Seeman & Seeman 1983) or reducing cigarette smoking and seeking information about health issues, (Strickland, 1978; Wallston & Wallston, 1986). However, people whose health locus of control is more external would be expected to feel less powerful in influencing their personal health outcomes and therefore, be less likely to practice health enhancing behaviours. Lefcourt (1991) noted that maximal predictions are best obtained if measures focus on particular populations and their concerns rather than those that rely on more global measures. Thus, measures that focus specifically on health issues, for example, would be more effective in determining related locus of control than measures used to more broadly determine general locus of control.

Research in relation to chronic illness has yielded more complex results. The diagnosis of a chronic illness may cause distress and anxiety as the individual faces uncertainty about how the illness will effect them, their family and their lifestyle. People diagnosed with chronic illness may feel helpless, as they experience feelings of loss of control over their bodies, their health and their lives. By developing a sense of personal control over the chronic illness and over life in general, people may counteract feelings of anxiety and helplessness (Taylor, 1983).

However, when dealing with chronic illness, a sense of control may

be illusory and, thereby, difficult to maintain in the face of continually uncontrollable symptoms. It has been argued (Taylor, 1983, 1989) that even an illusory sense of control can be helpful. However, others (Affleck, Tennen, Pfeiffer, & Fifield, 1987; Burish, Carey, Wallstrom, Stein, Jamison & Lyles, 1984) suggest that it is more adaptive to give up beliefs in control over chronic illness, than to experience ongoing and repeated failure when such control is ineffective.

Since most people with chronic illness are involved with ongoing treatment or review by medical and allied health care providers, research has suggested a positive effect of *vicarious* control (Folkman, 1984; Reid, 1984). That is, the experience that powerful others exert some control over the illness, its treatment and course. Taylor, Lichtman and Wood (1984), working with cancer patients, found vicarious control to positively associate with adjustment. However, Affleck et al., (1987) found that among patients with rheumatoid arthritis, perceived health care provider's control over symptoms was related to patients' negative mood.

To explore these apparent contradictions, Taylor, Helgeson, Reed and Skokan (1991) studied male and female cancer patients with prognoses ranging from cured or in remission, to advancing active cancers. They found that the relationship between vicarious control and adjustment was mediated by gender and severity of illness. Women with good prognoses were the only group to benefit from vicarious control. In regard to adjustment to

chronic illness “perceptions of control may be adaptive only when there is, in fact, something that can be controlled” (Taylor et al., 1991, p.106). However, they note that “even minimal amounts of control may continue to be adaptive” (p. 107).

In reviewing literature in the area, Heaven, Connors and Kellehear, (1991) noted that Locus of Control has implications for both behaviour and attitude. Research studies have shown strongly internal locus of control individuals to also rate themselves as powerful and independent (Hersch & Schube, 1967) and to have positive self-esteem (Epstein & Komorita, 1971). However, neuroticism (Feather, 1967) anxiety (Archer, 1979) and hostility (Heaven, Rajab & Bester, 1986) have been found in individuals with higher external locus of control. Since these attributes may also impact on a person’s attitude to life, it can be expected that those with a high internal locus of control would have a more positive attitude to life in general after diagnosis of a chronic illness, than those who are rated as externalising a health locus of control.

Self-Concept

Self-concept refers to the particular package of ideas and attitudes we have about ourselves at any given moment¹. Hamachek (1987) notes four separate, but interrelated components of self-concept: social, emotional,

¹ While self-concept refers to the idea we have of ourselves, self-concept is evaluative and refers to how we value the ideas we hold about ourselves. Further elaboration of self-esteem is provided later in this chapter.

intellectual, and physical. While each of these can be viewed as unique, it is important to consider how changes in one component may affect another. For example, changes in the physical self-concept of a professional sportsperson may be the result of the onset of a chronic illness and may end a promising career. This then may reduce the level of risk the person is prepared to take with their social self, as well as the style of social interaction they experience.

Congruency

The self we perceive of ourselves may not be similar to the self we really are, or to the self we would like to be. Where there is overlap or agreement between each of these aspects of self, there is said to be congruency (Hamachek, 1987). Research findings and clinical observations (Raskin & Rogers, 1989; Rogers, 1963) suggest that "high levels of self-congruency are related to a greater likelihood of psychological health" (Hamachek, 1987, p. 12). It is evident that, even when an individual experienced high congruency of these aspects of self, the implications and physical, social, and emotional changes brought about through the onset of chronic illness, may be detrimental to the self-concept and result in greater disparity between the aspects of self, particularly contrasting the ideal self and the real self. Generally speaking, the greater the gap between the aspects of self "the more likely it is that we will be victims of various forms of worry, depression, and low self-esteem" (Hamachek, 1987, p. 12). Usually,

when self-concept is low in one or all areas, so too is self-esteem.

Self-Esteem

Self-esteem is the evaluative component of self-perception, and is formed from our evaluations of what we do, who we are and what we achieve. Importantly, these evaluations are made in terms of the individual's assessments of value. That is, the individual's personal notion of what is good, valuable, important, or significant. A debilitating disease may have profound implications and ramifications upon self-esteem. This is particularly true with respect to chronic illness, which is persistent and, usually, unrelenting. People diagnosed with a chronic illness may experience changes to one or more aspects of their 'self', which are at odds with the characteristics they have previously valued. As these changes persist or worsen, they may then experience ongoing self-devaluation and consequent decreasing self-esteem.

Social Comparison

How people feel about themselves depends largely on how they compare themselves with others (Breakwell, 1986; James, 1890). Some (e.g., Cooley, 1902; Manis & Meltzer, 1974; Mette & Riskin, 1974) suggest that "the most potent comparison information is derived from people who [we perceive as]...similar to us" (Hamachek, 1987, p. 15). In light of this information, people with chronic illness are in a dilemma. If this person makes comparisons with healthy individuals they may readily identify areas

wherein they see themselves lacking: they may have less energy, decreased visual acuity, be less able to balance, be unable to walk or stand, their speech may be effected, they may have lost or been forced to change their job, they may be unable to fulfil an active role in many areas of their life. If people with chronic illness compare themselves to other people with chronic illness there is the possibility of identifying some comparative strengths, however, in positioning themselves in this group they must now also face the problem of positioning themselves in the outgroup.

Such a conception is consistent with the theories of Goffman (1963) who more closely examined the in-group/out-group contrast. In Goffman's terms of chronic illness this may mean identifying with, and as, a stigmatised individual. By aligning themselves with the outgroup, they risk aligning themselves with a group of less value and esteem, according to their previously held personal beliefs.

Personal Aspirations

The level at which the individual sets his or her personal aspiration is important to feelings of self-esteem because it helps establish what is regarded as a success or a failure. This can vary between individuals, and success in terms of one individual may be failure in the terms of reference used by someone else. As Allport (1937) argued "an adult...undertakes that amount and that kind of labour which will keep his (sic) self-esteem at a maximum ...[because] his (sic) most coveted experience is the enhancement

of his (sic) self-esteem, his (sic) most ineradicable trait is vanity" (p. 169).

The ability to set personal goals is at least difficult for people with chronic illness. They must balance their previous abilities with their, often, unknown current abilities (or disabilities). Consequently, they are confronted with significant dilemmas over the setting of goals and the balancing of pre and post diagnosis abilities and goals. Such dilemmas may also add to the decrease of feelings of self-esteem, and the likelihood that the individual cannot achieve what they perceive to be success. It may also decrease their opportunities for positive reflected appraisals from which they can build self-esteem.

Another important factor is the individual's history of successes or failures. "The impact of falling short of our personal aspirations stands to be a less self-deflating experience if our list of successes...exceeds our tally of failures" (Hamachek, 1987, p. 17). Taking a global perspective of the individual's self-concept places the chronic illness patient in poor standing in regard to history of successes and failures. The effects of chronic illness can result in the individual experiencing many situations that may be interpreted as failures. These failures, (e.g., failure to walk, to stay awake, to control tremor, to hold down a job, to engage in social activities, to participate in family outing) may build to the extent that the impact of falling short of personal aspirations, either short term or long term, may be even more potent. People with chronic illness may fall short of personal

aspirations in regard to every day living, such as being able to go out to dinner, and also in regard to long term goals. These long term goals may include pre-diagnosis goals such as running a marathon, or building a successful business, or post-diagnosis goals such as staying out of a wheelchair. In either case, a person with chronic illness must face a wide and varied range of repeated 'failures'.

Allport could easily have been speaking about a person with chronic illness when he wrote:

when failures are recurrent...they cannot be so easily disposed of. A tension not relaxed by fulfilment is present in a latent state and always ready to cause trouble whenever the desire for the unattainable goal returns. As a result a deep-seated sense of deficiency may develop and be steadily aggravated (1937, p. 173).

People usually assess their success in one or more of four categories (Coopersmith, 1967). First, power, which refers to the ability to influence and control people. Second, virtue, stressing adherence to certain moral and ethical standards. Third, significance, which entails acceptance, attention, and affection of others. Fourth, competence, which refers to successful performance in meeting demands for achievement. The far reaching and all encompassing ramifications of chronic illness may collectively or individually effect the individual's assessment in all four of these categories.

Feedback From Others

The sort of reflected appraisals individuals receive from those in their social world effects the individual's feelings about themselves (Banaji & Prentice, 1994; Gergen, 1972; Schlenker, 1980). However, changes in feelings of self-esteem are not always related to feedback from others (Shrauger & Shoeneman, 1979). Reflected appraisals may have only minimal impact in individuals whose actual abilities are predominantly responsible for both their self-evaluations and the evaluations they receive from others. However, in the case of a person with chronic illness, whose actual abilities may have diminished, whose self-evaluation is less than optimal, and who may already be questioning their self-worth, reflected appraisal (which is likely to be negative, particularly if they show obvious signs of their illness such as tremor, speech impediment, or using a walking aid) may have a great impact on their feelings of self-worth and self-esteem. Moreover, an individual who projects positive self-esteem (e.g., confidence in personal ability) is more likely to elicit positive feedback (Hamacheck, 1987). Thus, the individual dealing with a diagnosis of chronic illness is disadvantaged as they are less likely to project positive self-esteem, or may actually project negative self-esteem, thereby inducing an increased incidence of negative feedback. Self-esteem and reflected feedback are mutually reinforcing. Given the multitude of reasons that each of these may be negatively effected by chronic illness, we would expect changes in self-

esteem and self-worth in individuals who have chronic illness.

Theoretical Advances in Self-Concept

Another body of work focussing on various aspects of self-concept is that of Marsh. Much of his work evidenced support for the construct validity of self-concept, and the notion that self-concept is multidimensional and hierarchically arranged (Marsh, Relich & Smith, 1983; Marsh, Smith, Byrnes & Butler, 1983; Marsh, Smith & Barnes, 1984) Marsh, et. al., noted that “the formation of self-concept is affected by different processes than the self-concepts inferred by significant others” (p. 367) and that self-concepts are affected by different processes than the achievements they reflect. So, in order to be understood, self-concept must be viewed multi-dimensionally.

Extending the application of this work to broader age groups led Marsh and Shavelson (1985) to note that different facets of self-concept become more distinct with age. Later exploration of the dimensions of self-concept, confirmed that self-concept was relatively stable from pre-adolescence to early adulthood (Marsh, 1989). This is important to note, and supports the parameters of the present research in looking at adult onset chronic illness as a way of determining the impact of chronic illness on individual's who have a formed sense of self.

Subsequent research looked at the relationship between self-concept and self-esteem. Differences in self-esteem were not explained by the importance individuals placed on different facets of self-concept (Marsh,

1986), except in relation to the spiritual and physical facets of self-concept. Most variation for the emphasis placed on the various facets of self-concept was found for these two facets. These findings can be related to research on chronic illness, where the illness may cause greater variations in physical ability, variously represented as mobility or disability, and this may then focus the individual's attention on that facet. That is, circumstances related to the illness may increase the importance or emphasis placed on physical ability. This is possibly explained by examining physical self-concept in relation to reflected appraisal, as discussed earlier. This may then go some way to explaining variation in self-esteem related to chronic illness.

Later findings (Marsh, 1987), can also be applied to the case of living with chronic illness. That study found a clear hierarchy related to esteem and the physical, social and emotional components of self-concept. In chronic illness, the changes in the physical self-concept may result from changes in physical abilities, strength, or possibly, appearance. As these changes in physical ability potentially limit social opportunities and change the individual's social roles, there may be changes to the individual's emotional responses to such change and to life in general. Thus, the impact of chronic illness on all of these facets of self-concept may explain changes in self-esteem.

Further application and testing of Marsh's work confirmed generalisability (Marsh & Byrne, 1993, Marsh & Smith, 1987), explored sex differences (Marsh, 1989), and developed constructs of multidimensional physical self-concept (Marsh, 1994a; Marsh & Sonstroem, 1995), and academic self-concept (Marsh, Smith & Barnes, 1984; Marsh, et. al., 1984; Marsh & Yeung, 1997).

Self Discrepancy Theory

A new direction in the study of self-concept explored perceptions of different self-states – the actual self, the ideal self and the ought self (Higgins, Bond, Klein & Strauman, 1986). The ideal and ought self are seen as two distinct self-guides, which the individual refers to in order to regulate themselves (Higgins cited in Kavanagh, Glick, & Fein, 1994). The ideal self is conceptualised as “their own or others’ hopes and goals for them”(Higgins, et al., 1986, p. 5) and the ought self is conceptualised as “their own or others’ beliefs about their duty and obligations” (p. 5). While self-discrepancy theory originally focussed on discrepancy between the actual self and the ideal or ought self, later work (Higgins, 1987, 1989) explored the implications of additional self-belief types. These were the can self and the future self.

The can self is conceptualised as “a representation of someone’s beliefs about your capabilities or potential” (Higgins, Tykocinski, & Vookles, 1990, p. 171). The future self is conceptualised as “a

representation of someone's expectations about the type of person you will become" (Higgins, et al., 1990, p. 171).

Later development of the theory further explored the effect of self-belief patterns. For example, chronic or repeated failure to meet expectations or hopes showed that there were a variety of psychological significance of the discrepancy dependent on "whether the meaning of the positive end state is defined by the ideal matching self matching the can self or the future self" (p. 181).

This theory views discrepancy between actual self and self guides as explaining many emotional and psychosocial reactions to life situations, and can readily be applied to the context of people with chronic illness. Clearly, there are a myriad of interpretations wherein the individual with a chronic illness will perceive discrepancy between how they actually are and how they wish to be, or how they or others, think they ought to be. Given the potential for fluctuations in symptoms, lifestyle, relationships, and perception, which may be associated with chronic illness, there may be a succession of changing discrepancies to be dealt with.

Further support for the existence of distinct ideal and ought self-guides was provided by Boldero and Francis (1999) who concluded that their findings of the existence of moderator variables for the relationship between discrepancies and behaviour of emotion, indicate the unique nature of the self-guides because of the differential effect the moderator variables

have on each. This theory has been shown as useful in many applications, including health issues (Higgins, Vookles & Tykocinski, 1992), and in other areas which can be seen as relating to the psychosocial sequelae of chronic illness, such as maintenance of social contacts (Higgins, Roney, Crowe & Hymes, 1994).

Work on the self is diverse (e.g., comparing self-other agreement in self-concept, Marsh & Byrne, 1993; reconciling self-enhancement and self-verification, Swann, Pelham & Krull, 1989; concepts of self in crises, Treacher, 1989) but may be broadly categorised as either centred in self-knowledge or self-enhancement. Self-knowledge refers to the desire for accurate and certain evidence about one's abilities and traits and for evidence that confirms one's self-assessments. Self-enhancement refers to the desire for positive feedback. Interpersonal contexts are important in this search for evidence about oneself because they "provide expanded opportunities for the pursuit of self-knowledge [and] self-enhancement" (Banaji & Prentice, 1994, p. 302).

The effects of chronic illness may limit interpersonal contexts for the individual. Furthermore, given the uncertain prognosis for many people with chronic illness, and the daily fluctuations in abilities experienced, self-knowledge may be elusive. Thus, changes, which result from chronic illness, including changes of mobility, may bring about changes in one or more components of self-concept.

Threats to Self-Identity

Concepts of self are clearly related to contextual or social factors that the individual must process. In agreeing that the self or identity can be viewed as a social construct, Breakwell (1986) developed a heuristic description of the social context, in two dimensions: structure and process. The structure is represented by the matrix of interpersonal relationships within which the individual exists, and includes group distinctions (for example such social categories as gender). The second dimension, the process of social influence, is the activity of the structures of the social context, through which the individual is influenced and shaped.

Breakwell (1986) further developed a theory of threatened identity, whereby threats are seen to challenge either the content or the value dimensions of identity. On the content dimension, threats "challenge the continuity or distinctiveness of self-definition. They query whether you can continue to be what you think you are" (p. 48). In regard to the value dimension "threats challenge self-esteem. They query whether what you are is any good" (p. 48). Applying this theory to chronic illness also results in a rather negative picture for people with chronic illness who face daily questions of being able to continue being what they thought they were, and whether what they are now is any good.

Conclusions

Chronic illness, potentially, has many and varied outcomes for the

individual's sense of self. Therefore, the self as a social construct and the importance of social identity are clearly relevant. Furthermore, when the use of mobility aids becomes an issue, it follows that the Symbolic Interactionist approach, which argues that individuals respond to things depending upon the meaning those things hold for them, and, that no particular response is inherent in anything external but is dependent on the context within which the interaction occurs (Olsen & Zanna, 1993), is a useful perspective from which to view mobility issues and their effect on attitude in chronic illness patients.

Theory Relating to Mobility

Symbolic Interaction

As well as theoretical perspectives in regard to issues of mobility discussed earlier, this thesis will also explore the issue of mobility within the framework of a Symbolic Interactionist approach. Symbolic Interactionism arises from the work of such researchers as Cooley (1902) who introduced the concept of the 'looking glass self'. Cooley suggested that individuals imagine how their acts will be perceived and judged by others, then experience feelings such as pride or embarrassment and adjust their behaviours based on these feelings. Similarly, Blumer (1969) argued that "human beings act toward things on the basis of the meaning that the things have for them" (p. 2).

Individuals, within a symbolic interactionist approach, are the centre

of attention and interpret social reality in terms of their own acts and the acts of others. It is particularly useful to examine issues of chronic illness, and the related theme of mobility, using this framework, particularly through the work of Goffman (1963) and his theory of stigma.

Theory of Stigma

Historical Perspective

The term stigma was originally used by the ancient Greeks to refer to bodily signs designed to expose something bad about the moral status of the signifier and to advertise that they be avoided, especially in public places. In later Christian times, the term was metaphorically used to refer to either bodily signs of holy grace, known as stigmata, or bodily signs of physical disorder. However, in contemporary times the meaning of stigma is closer to the original literal sense, although it is applied more to disgrace than to the bodily signs of that disgrace. Thus, the Concise Oxford Dictionary (1969) lists a meaning for stigma as "imputations attaching to person's reputation: stain on one's good name" (p. 1262).

The Theory of Stigma

According to Goffman (1963), whether or not a particular piece of information about an individual is a stigma, depends on the context and the perceiver. Stigma can range from "abominations of the body", such as skin blemishes or deformity, to character blemishes, such as weak will or unemployment and, finally, to the tribal stigma of race, nation and religion.

However, in all instances "an individual who might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he [sic] meets away from him [sic], breaking the claim that his [sic] other attributes have on us" (p. 5). Consequently, the individual is judged wholly on the basis of the stigma, from which a wide range of characteristics are imputed.

Stigma and Chronic Illness

This process of stigmatisation is relevant to individuals with chronic illness, in several ways. Firstly, people with chronic illness who have obvious physical manifestations of the disease such as tremor, or who need to use mobility aids (such as walking sticks and wheelchairs) may bear the stigma of their changed physical appearance (with tremor, or 'unnatural appendages'). This may compound the original source of the stigma (having chronic illness) when individuals reject using mobility aids, and risk exacerbating their condition (e.g., through falls or consequent social isolation). Goffman explains this as "the physical equipment used to mitigate the 'primary' impairment of some handicaps understandably becomes a stigma symbol, [thence] there will be a desire to reject using it" (p. 92). Secondly, the label of 'chronic illness patient', disabled person, cripple, clearly stigmatises the individual to whom the label is applied. However, the chronic illness patient is faced with many more potential stigma, such as being unemployed, being accused of 'not trying hard

'enough', or being unable to fulfil social roles that they used to do or that others deem they should do.

Moreover, aspects of stigma interrelate with concepts of social identity, the concept of self and group alignment, emphasising problems in these domains, and, thereby, further highlighting the intensely difficult experience of the individual diagnosed with a chronic illness and dealing with the subsequent effects of the illness.

Physical Mobility and Chronic Illness

Issues of mobility, ambulation, or physical disability have been identified as important in determining the overall psychosocial profile of chronic illness patients. Not only is physical disability one of the most stressful factors associated with chronic illness (Beulow, 1991), associated physical restrictions also negatively affect self-esteem (Elliot, McNair, Herrick, Yoder & Byrne, 1991; Walsh & Walsh, 1987, 1989). Functional loss is a "significant determinant of the emotional impact of chronic illness" (Devins & Seland, 1987, p. 370) and emotional disturbances are associated with increased disease exacerbation and somatic complaints, typified by increased physical restriction (Dalos, Brooks & O'Donnell, 1983).

The problems associated with chronic illness are particularly evident in the workplace. Mobility problems associated with chronic illness have been related to problems with cognition, job adjustment, personal attributes and work performance (Gulick, 1992). Such difficulties place people with

chronic illness in an unenviable situation since ambulation difficulties are a significant determinant of employment status, with impaired mobility resulting in higher rates of unemployment (Edgley, et al., 1991), and negative attitudes from self and others.

Attitude Theory

Definition

The importance of understanding and measuring attitudes has been discussed by many (e.g., Ajzen & Fishbein, 1980; Allport, 1929; Fishbein & Ajzen, 1975; Olsen & Zanna, 1993), but is clarified by Rajecki's observation that

Attitudes get us to act in certain ways... to do things in an orderly and coherent fashion. Generally we are consistent because of our attitudes. Knowing a person's attitudes gives us confidence that we can predict or anticipate actions in general (1990, p. 6).

A basic question about attitudes is the nature of the concept itself (Olsen & Zanna, 1993). While there is a long history of research on attitudes, there does not appear to be a singular definition. Attitudes have been seen as verbal fictions and psychological realities (Allport, 1929). In 1929 Allport defined an attitude as:

a disposition to act which is built up by the integration of numerous specific responses of a similar type, but which

exists as a general neural 'set', and when activated by a specific stimulus results in behaviour that is more obviously a function of the disposition than of the activating stimulus (p. 221).

He later refined his definition and subsequently provided a comprehensive definition of attitudes as "a mental and neural state of readiness, organised through experience, exerting a directive or dynamic influence upon the individual's response to all objects and situations with which it is related" (Allport, 1935, p. 799). Later theorists have variously defined attitudes in terms of cognition (for example, "a special type of knowledge, notably knowledge of which content is evaluative or affective" (Kruglanski, 1989, p. 139), evaluation (for example, "a psychological tendency... expressed by evaluating a particular entity with some degree of favour or disfavour" (Eagly & Chaiken, 1992, p. 34), affect (for example, "the affect associated with a mental object" (Greenwald, 1989, p. 432), and behavioural predispositions (e.g., "a state of a person that predisposes a favourable or unfavourable response to an object, person or idea" (Triandis, 1991, p. 485).

Despite acknowledging these differences, Olsen and Zanna (1993) see some agreement in the definitions of the various theorists. Firstly, evaluation is a central, perhaps predominant, aspect of attitudes. Secondly, attitudes are represented in memory. Finally, affective, cognitive and behavioural antecedents, as well as consequences, of attitudes can be

distinguished. Ultimately, the traverse of years leaves us no closer to a singular definition of attitude, and the truth of Allport's observation remains relevant, "All definitions...are merely heuristic" (1929, p. 221).

As attitudes are organised by experience (which would lead to particular behavioural beliefs and outcome evaluations, Fishbein & Ajzen, 1975; 1980) and subsequently direct the individual's response (Behaviour), Allport's (1935) definition is a pre-cursor to the Theory of Reasoned Attitude (Fishbein & Ajzen, 1975; 1980).

This thesis will focus on a model of how beliefs can determine attitudes, which was developed by Fishbein and Ajzen (1975, 1980). This theory, known as The Theory of Reasoned Action (TRA), is used to predict behaviour in many contexts. It remains dominant in the attitude-behaviour literature, and "inevitably it serves as the standard to which new ideas and theories are compared" (Olsen & Zanna, 1993, p. 131).

TRA has been used across a broad sweep of research. Recent diverse applications of the theory of reasoned action include, for example, smoking (Norman & Tedeschi, 1989); performing testicular self-examination (Steffen, 1990), participation of individuals with intellectual disabilities in mainstream recreation (Sparrow, Shinkfield & Karnilowicz, 1993), premarital sexual behaviour (Chan & Cheung, 1998), sunscreen use among children (Hoffman, Rodrigue & Johnson, 1999), condom use (Smith & Stasson, 2000), drink-driving intention (Gastil, 2000), fast food

consumption (Bagozzi, Wong, Abe & Bergami, 2000) and participation in tuberculosis screening programs (Poss, 2000).

Theory of Reasoned Action

Fishbein and Ajzen (1980) base their theory on the assumption that human beings are usually rational and make systematic use of the information available. Their ultimate goal was to "predict and understand an individuals behaviour" (1980, p. 5). According to the TRA, two components are important, one personal (attitudinal) and one reflecting social influence (normative). In addition, the theory states that "attitudes are a function of beliefs" (1980, p. 6).

While various other factors that may influence behaviour (e.g., demographic variables, social role, status, intelligence, authoritarianism) are considered external to the theory, Ajzen and Fishbein do make the important point (that relates to the present study), that:

"Some external variables may bear a relation to the behaviour under investigation, ... [but] ...it may change over time and from one population to another..., an external variable will have an effect on behaviour only to the extent that it influences the determinants of that behaviour"(1980, p. 9).

This is best understood by referring to Figure 1.

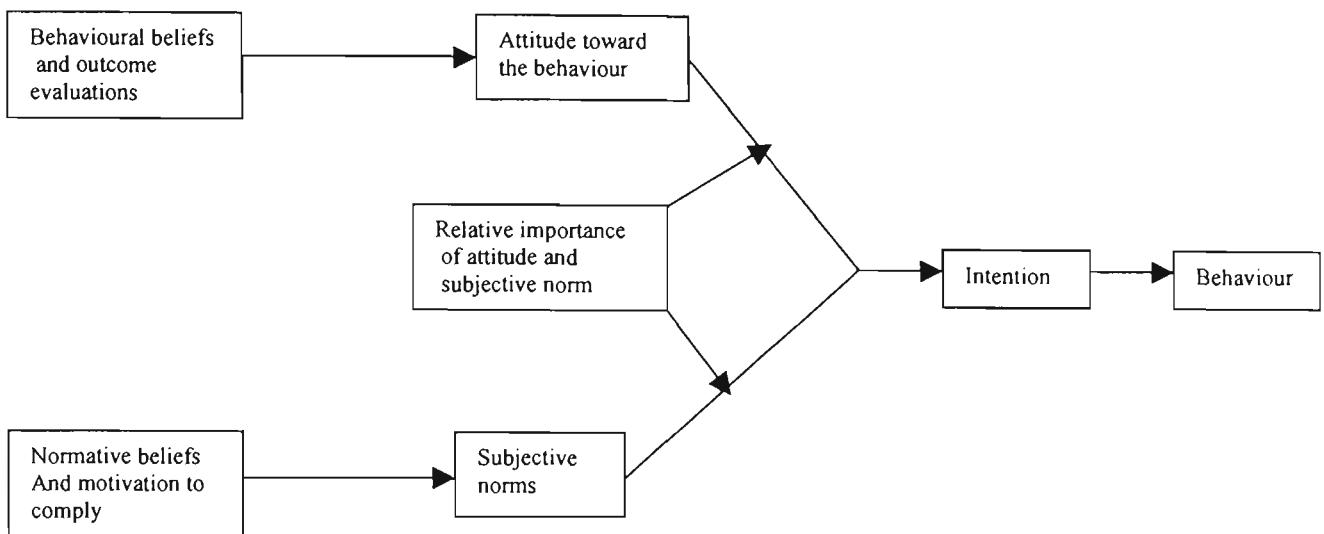


Figure 1: The Ajzen and Fishbein (1980) Model of the Theory of Reasoned Action.

This figure shows the relationships between the factors in TRA that determine a person's behaviour. The model suggests that people behave in accord with their conscious intentions, based, in turn, on their rationale evaluations about the effects of their behaviour and what other people will feel about it. When examining chronic illness, in the context of this figure of the Fishbein and Azjen model, these external variables (such as mobility) would act to influence at the stage of behavioural belief and outcome evaluation and would therefore have an effect on attitude. Attitude, as a determinant of intention to behave, thereby influences the behaviour itself.

More detailed explanation of the methodological approach relating to the Theory of Reasoned Action is contained in Chapter Four.

CHAPTER 3

LITERATURE REVIEW

Chapter Two provided the theoretical framework within which this thesis sits presenting theoretical perspectives relating to self. Locus of control, self-concept, self-esteem, self-discrepancy and threats to self identity were discussed in relation to chronic illness, while issues of physical mobility were used to highlight the application of each of the theories to understanding chronic illness. Mobility was discussed from a symbolic interactionist approach, highlighting the effects of using visible mobility aids.

This chapter will move to a more applied perspective. However, since the link between theoretical perspectives and clinical research is not always apparent, the literature is examined in the categories of coping and adjustment, quality of life, research with children (which is the focus of a large body of work within the chronic illness literature), compliance, mobility, disease specific studies, and finally, the recent work which suggests the importance of a more global perspective.

Coping and Adjustment

Many researchers have examined coping strategies as a way of understanding adjustment to chronic illness. For example, the relationship of

stress appraisal and coping styles to illness adjustment in adults was examined by Bombardier, D'Amico, and Jordon (1990). This study focussed on identifying coping styles that were associated with poor psychosocial adjustment, identifying wishful thinking, self-blame and avoidance as maladaptive.

A more recent review of coping and illness in relation to chronic fatigue syndrome (Ax, Greg, & Jones, 2001), suggested a possible association between coping, and physical and psychological well-being. It is plausible that these findings would extrapolate to other chronic illnesses. Thus, their suggestions for longitudinal research on coping and therapeutic intervention, may also be sound advice in regard to other chronic illnesses.

Brown, et al. (2000) support the notion of an association between coping and disease adjustment, in an indirect way. They examined children with sickle-cell disease and their primary care givers, finding an indirect effect on child adjustment by primary caregiver's coping. Interestingly, the child's adaptation to the disease was associated with an internal health locus of control. The scope of disease-specific studies exploring coping and coping strategy was broad and covered many diseases, for example, HIV (Leiberrich, et al. (1997) and breast cancer (Buddeberg, Wold, Sieber & Reihl, 1991).

While research has failed to definitively identify factors in adjustment to illness, it has been noted that adjustment is, nonetheless, an

important consideration. For example, Barnett-Wislon (1992) noted that anxiety and discomfort associated with many medical procedures may be reduced by appropriate psychological intervention. However, they were diligent in pointing out that consideration of adjustment to illness and chronic symptoms is important when providing psychological interventions aimed at reducing psychological and physical discomfort.

As early as 1984, Felton, Revenson and Hinrichsen examined psychological adjustment among chronically ill adults. While their research did relate different coping strategies to positive and negative affect, they were unable to find a strong link between coping strategy and medical diagnosis. Thus, they were generally unable to explain adjustment and concluded that new research approaches were needed.

Quality of Life

Many studies acknowledged quality of life as an important variable. However, measurement of quality of life is inconsistent ranging from self report to external observer modes, and a combined method developed by Gottschalk and Lolas (1992). Again, studies were disease specific. For example, renal disease (Koch & Muthry, 1990), cancer (Muthry, Kock & Stump, 1990), endocrine disease (Sanino, Fava, Fullo & Boscaro, 1991), cardiovascular disease (Mayou, 1991), inflammatory bowel disease (Kuensebeck, Koerber & Freyberger (1991). A study by Tope, Ahles and Silberfarb (1993) acknowledged psychological well-being as a component

of quality of life but used psychiatric diagnoses as their measure of quality of life. In so doing, they do not demonstrate a strong understanding of the psychological domain.

Chronic Illness in Children

Considerable research interest has been directed at chronic illness in children, but has still largely been dominated by disease-specific studies. Hurtig, Koepke and Park (1989) tested for the relationship between adjustment and illness severity in juvenile sickle -cell anaemia patients. Illness severity was measured by frequency of a number of discrete variables such as clinic visits. Their hypothesis, that illness severity would affect adjustment, was not supported. They noted that other variables, such as family structure or support systems, may have suppressed the hypothesised relationship. This highlights the problem of not considering the individuals' perspective and not considering social support structures.

In contrast, Bech (1993) reviewed various models for the measurement of quality of life in chronic disorders. This study discussed approaches in terms of the patient's consideration of the various components of life and adjustment. Another study of the psychosocial impact of chronic illness in children (Northern, 1997) highlighted the differential medical role faced by physicians in caring for a child in either a chronic or an acute illness. It was suggested that chronic illness and its treatment may compromise intellectual and academic development of

children. A study by Gartstein, Short, Vanath and Noll (1999) also examined psychosocial adjustment of children with chronic illness, assessing emotional, behavioural and social functioning. This study compared the effectiveness of theoretical models in addressing the psychosocial impact of chronic illness and provided support for the non-categorical rather than the discrete disease model. Although this study focussed on children, the conclusions further support the non-disease specific approach developed in the present research.

Other research involving children and related to chronic illness has explored the adjustment of healthy children to siblings' chronic illness (Drotar & Crawford, 1985), and understanding the impact of chronic illness on the family of people with chronic illness (Zorski, West, De Pompei & Hall, 1988). Christie, French, Weatherstone and West (1991) focussed on quality of life and children's' perceptions of asthma and its treatment. They highlighted the need for holistic appraisals of general well-being.

Compliance

Another area of research interest in regard to chronic illness is largely related to compliance issues. For example, Powers and Jalowsic, (1987) identified well-adjusted hypertensive patients as knowing what to do about medication side effects and being on medications longer. They identified well-controlled patients as those who were less likely to eat, smoke, or use drugs to handle tension. This study did give minimal attention

to some psychosocial issues other than compliance, such as coping with stress, locus of control and satisfaction with treatment. Blackwell (1992) again examined compliance issues, noting that very few factors associated with compliance have been consistently identified. These studies suggest that issues of compliance, while important in that specific area, are not a useful perspective from which to view adaptation to chronic illness in general.

Mobility

Mobility not only involves musculoskeletal impairment but can be influenced by sensory loss, pain, or energy depletion. When the physical ability to move changes, psychological adjustment must occur. A part of the adjustment is a process of redefining self that requires reconstruction of self-image. The mobile, ambulatory person who has difficulty accepting restrictions in locomotion or agility finds that adaptation rarely entails an agreeable, acceptable, or easy change. The process of mobility in chronic illness is usually characterised by inconsistency, questioning and occasional hopelessness (Kohler, Schweikert-Stary, & Lubkin, 1990, p. 93).

Viemeroe and Krause (1998) investigated quality of life in individuals with physical disability. They found that life satisfaction was a function of meaningful occupational activities, social integration and sense of the meaning of life. This study did not clearly relate disability to life satisfaction or any of the factors associated with life satisfaction. Thus, it

failed to clearly explore the issue of disability. Stenager, Knudsen and Jensen (1991) found social problems increased with physical disability, and that physical disability was the most significant factor in physical and social well-being.

Antler, et al., (1969) adopted a more specific approach and examined patients' attitudes to the wheelchair. They found that attitude toward the wheelchair became less positive as patients impairment became more severe.

In contrast, Brooks (1991) found patients' perceptions to assistive devices were positive and that patients' perceptions of public response was accepting of the patient and the use of the device. However, that study used a mail survey of scientists and engineers as participants. The reported positive attitudes may be an artefact of these participants' position and lifestyle, due to their employment, education and income. Thus, the findings may not generalise to other populations.

In order to take account of previous research, and in consideration of the potential for deficits in mobility within the illness groups of interest, the present study will examine mobility as a variable of interest affecting attitude in people with chronic illness.

Disease Specific Literature

Since the bulk of chronic disease research to date has been disease-specific, the following sections review a broad cross-section of this literature in each of the diseases of interest.

Diabetes

Diabetes is a collection of conditions characterised by impaired glucose metabolism (Gregg, Robertus & Stone, 1989). Type I diabetes is the least common form, affecting 10-15% of all cases, usually diagnosed during childhood, and treated with insulin. Type II diabetes is the most common form, representing 85-90% of all cases, usually occurring in people over the age of 30. It is usually treated by changes in, and constant monitoring of, diet and exercise. Type II diabetes can cause long term complications such as serious damage to the eyes, kidneys, nerves and blood vessels. Thus, it is the biggest cause of non-traumatic blindness and amputation.

However, there is little apparent consensus in the literature related the psychological aspects of diabetes, except in acknowledging the psychosocial context as influential in the disease course and adjustment to the disease (Fisher, Delamater, Bertelson, & Kirkley, 1982; Johnson, 1980). Following the National Conference on Behavioural and Psychosocial Issues in Diabetes in the United States (Hamburg, Lipsett, Inoff, & Drash, 1980), the amount of research within this domain increased. For example, Dudley

(1980) identified the need for individualised education of patients in response to the unique circumstances of each patient. Surwit, Scovorn and Feinglos (1982, 1983) detailed the complex role of behaviour in diabetes care and management and concluded that the lack of clear rewards was often implicated in regimen compliance problems. A number of studies purported to take a psychological perspective, but were still largely centred on compliance and medical status rather than exploring psychological status of people with diabetes. For example, Orlandini, et al. (1997) examined personality traits and metabolic control; Aikens, Kiobasa, and Sobel (1997) looked for psychological predictors of glycemic change with relaxation training with very unclear results; and Petty, Sensky, and Mahler (1991) verified diabetologist's assessments of patients' emotional state, but based this largely on their perceptions of dependency on doctors and ability to cope with the disease. This study is conceivably tainted by doctors' perceptions of good patients.

Several researchers have applied standardised instruments measuring psychopathology, locus of control, depression, anxiety, self-esteem, and the identification of a 'diabetes personality'. However, these were often too broad in approach to target the specific issues associated with diabetes (Dunn & Turtle, 1981; Skyler, 1981). Subsequently, instruments were developed which were deemed appropriate for the assessment of change in response to short-term intervention strategies (Davis, Hull & Boutaugh,

1981; Dunn, et al., 1984). These instruments focus on educational aspects of regime maintenance and are suitable for assessing areas of diabetes knowledge wherein persons with diabetes were lacking.

As the health-belief model gained popularity, attitude research in diabetes began to concentrate on disease-specific health beliefs and their relationship to compliance and metabolic control (Harris & Linn, 1985; Simonds, Goldstein, Walker, & Rawlings, 1981; Schafer, Glasgow, McCauly, & Dreher, 1983). Thus, researchers assessed and investigated the psychological and social parameters of this disease. Dunn, Smartt, Beeney, and Turtle (1986) argued that "the emotional component [from] the classic tripartite theory of attitude and attitude change, [had largely] been neglected" (p. 480), and consequently developed a measure of emotional adjustment in diabetic patients. Hess, Davis, and Harrison (1987) identified a major goal of patient education as enhancing "the ability of patients to comply...and to cope with the implications of a chronic disease and its impact on their lives" (p. 135). They developed a lengthy 110-item questionnaire to access attitudes, beliefs, behaviours and knowledge in relation to diabetes. They stated that this instrument was able to "determine the educational and counselling needs of patients with diabetes (p. 140)". However, the instrument did not address issues of social support.

Several researchers found that control and regimen adherence were positively associated with social support, belief in disease severity and

belief in the benefits of regime adherence, while control and regimen adherence were negatively associated with stress, depression, perceived regimen complexity, and perceived barriers to adherence (e.g., Lustman, Griffith, Crouse & Cryer, 1986; Schafer, McCaul & Glasgow, 1986; and Wilson, et al., 1986).

The psychosocial correlates of diabetes indicate that diabetes is associated with lowered self-esteem, anxiety, mood disturbances, and increased depression (Sullivan, 1978; Swift, Seidman, & Stein, 1967). However, these studies were limited to children and adolescents, and have not been replicated in recent times. Therefore generalising these results to the present day, and to an adult sample, is difficult. Connell (1990) concluded that "health status is related to psychosocial outcome measures, including morale, life satisfaction, quality of life and depression" (p. 93), but noted the paucity of research exploring the predictive power of health variables specific to chronic illness in regard to psychosocial outcomes, especially among adults. Connell argued the need for an increased awareness and understanding of the potential psychosocial ramifications of poor management of chronic illness, the potential changes to an individual's social support network subsequent to diagnosis as a result of the effects of the illness and/or illness management process, and for an improved understanding of the relationship between overall physical health, specific

physical health outcomes associated with chronic illness and psychosocial variables.

Welch, Smith, and Walkey (1992) mooted that attempts to define, understand and measure psychological constructs have not kept pace with the biomedical research in relation to diabetes. Research in the psychological realm of chronic illness, particularly diabetes, has only begun in the last decade, and still leaves a poor understanding of the “unique nature of the psychosocial problems of people with diabetes” (p. 649). Cleaver and Pallourios (1994), similarly noted the paucity of studies relating to psychological factors of diabetes. Adopting a phenomenological approach, they highlighted several aspects of the disease as being more profound and varied than previously suggested. Specifically, patients experience difficulty with the impact of the diagnosis, the first onset of symptoms and the experience of daily injections. Furthermore, Cleaver and Pallourios focused on the many causes for social isolation, individual and family stress, fear, and reactions to and feelings about these fears. The lack of research in the psychological area is evidence that the excitement and endeavour generated by a 1980 conference on the topic waned considerably after the first five years, leaving much work to be done to adequately attend to the issues at hand.

Arthritis

Arthritis consists of 150 forms, ranging from mild to severe symptoms, the most common being persistent pain, swelling or stiffness in one or more joints. In its severest form, arthritis may cause gross deformity of joints and result in total lack of use of effected areas, causing inability to write, dress or walk (Arthritis Foundation of Victoria, 1997).

Research in psychological factors associated with Rheumatoid arthritis (RA) has emphasised the consequences of the disease for psychological and behavioural status (Young, 1992), as well as identifying the psychological variables that impact on disease course or symptoms. Young asserts that “research [has] clearly demonstrate[d] the importance of psychological factors throughout the course of this disease” (p. 625). While it is clear that cognitive-behavioural interventions have enhanced the ability of persons with RA to cope with the negative aspects of their disease (eg., Lorig, Lubeck, Kraines, Seleznich, & Holman, 1985; O’Leary, Shoor, Lorig & Holman, 1988), it is yet to be ascertained how enduring the changes that result from such therapeutic interventions are to be.

Acknowledging that many studies related to patient satisfaction, or equivalent measures, have been conducted in general populations, Ross, Sinacore, Stiers, and Budiman-Mak (1990) highlighted the scarcity of such research in relation to patients’ coping with specific diseases. After reviewing many studies and critiquing research to date, they proposed two

hypotheses for future research: that patients with arthritis were a unique group and have unique expectations of health care, and that they may differ or be similar to other chronic illness groups, and that there may be within group differences.

Several studies have considered the importance of particular aspects of health care, from the patient's perspective. These studies point to the existence of differences within groups (dependent on variables such as age, acute versus chronic illness (Fletcher, et al., 1983), and whether patients valued psychosocial aspects of care more highly than technical aspects of care (Linn, Dimmatteo, Chang, & Cope, 1984).

Affleck, Pfeffer, Tennen, and Fifield (1988) in a quantitative and qualitative examination of the relationship between social support and psychosocial adjustment to rheumatoid arthritis (RA), concluded that higher levels of social support related to improvements in functioning, mood, self-esteem, and overall psychological well-being. However, they only accounted for a small amount of the variance in the results. This work highlights the need to measure/gauge individual responses and needs subsequent to diagnosis.

In a more extensive, longitudinally designed study (in terms of psychosocial variables) Smith, Dobbins, and Wallston (1991) were unable to find strong evidence for perceived competence as a mediator of adjustment to RA. Unfortunately this study covered a time span of only six

months, and results were characterised more by stability of response than by changes in response. Smith, et. al., concluded that "the social and psychological resources that promote perceived competence and, thus, weaken the relationship between illness and poor adjustment await considerable clarification" (p. 1238), and further, "that the relationships observed ... should ... apply to a variety of debilitating diseases" (p. 1240).

Buckley, Vacek, and Cooper (1990) surveyed persons with RA to determine their preferences in sourcing information and help with issues related to their disease. While the majority preferred to seek help from physicians, large percentages of patients were willing to attend groups (75%) and see individual counsellors (68%). While confirming the importance of educational and psychosocial issues for persons with RA, this study did not identify any issues or areas of concern that were specific to the RA group. However, differences were found within the RA group in that disease severity implicated psychosocial issues as at least equally important as educational issues, and women rated the effects of arthritis on their self-image as important and negative. However, statistical significance of this trend was questionable and may have been effected by the relatively low proportion of men in the survey (25%). The researchers also failed to acknowledge that persons with more severe disease effects may have had the disease longer and may have obtained adequate educational information, thus explaining the apparently higher focus on psychosocial issues when

compared to those with less disease severity. Overall, this study was quite inconclusive.

Based on the premise that depression is the "most common and debilitating psychological symptom associated with RA" (Beckham, D'amico, Rice, Jordan, Divine, & Brook, p. 539, 1992), Beckham, et al. studied the degree to which depression is related to psychosocial and physical dysfunction in persons with RA. They were able to attribute a large proportion of variance to depression. However, the study was very limited in terms of sample size and representativeness. Moreover, it employed only a single measure of disease severity and level of functioning. Clearly, generalizability of the results of such studies must be questioned.

Smith and Wallston (1992), in a complex and comprehensive study of appraisal, coping, and adaptation in persons with RA, provided insight into the complexity of issues facing persons with RA, and the usefulness of research which endeavours to address a more global picture. However, their findings were not clear, and did not consider potential interactions among variables. Similar results for coping and psychosocial adjustment were found by Long and Sangster (1993), wherein pessimism was associated with poor adjustment through greater use of wishful thinking coping. They also contended the need to examine multiple stressors faced by persons with RA. In addition, the latter research indicated that persons with RA may have unique needs regarding their overall psychosocial adjustment.

Taal, et al. (1993) examined the effect of group education for persons with RA. The education program implemented was based on social learning theory, and the 'Arthritis Self-Management Course' developed in the USA by Lorig (1985). Interestingly, Taal, et al. found no changes in psychological and social aspects of health status, but did find behavioural change following the course. Moreover, they failed to find any changes in overall health status regardless of the physical and behavioural changes found subsequent to the course. It is apparent that other variables were acting on the overall health status measure, and this may point to the need to examine psychological variables more fully. Beuchi, Sensky, Sharpe and Timberlake (1998) applied a novel measure of patient's perception illness impact, which they believe measures "the burden of suffering (p. 307)" .

An interesting development was the use of self-rated functional status by Radanov, Schwarz, Frost and Augustiny (1997). They looked for a relationship with psychosocial stress in patients with rheumatoid arthritis. However they failed to consider the patients' cognitions and feelings about their functional status and were left to rely on personality factors for explanation of their findings.

Stroke

Stroke is a condition in which damage to the brain occurs as a result of disruption to blood supply. Stroke or cardiovascular accident causes subtle to severe behavioural, intellectual and memory changes (Kolb &

Whishaw, 1996). The most common deficits after stroke are paralysis such as being unable to move one side of the body resulting in inability to walk, dress or manage usual daily activities, impaired cognitive functioning, such as being unable to process language, to read or write, and emotional disorders, such as being unable to interpret or react to emotions.

Research related to psychosocial factors in stroke is limited in number and scope, most often focusing on social support issues while concurrently not considering other psychosocial issues. For example, Atler and Gliner (1989) used structured interviews to assess the effect of three specified psychosocial variables (spouses' attitudes, spouses' social support networks, and family cohesion and adaptability) on activity levels in thirty male participants over fifty years of age. The results of this study were inconclusive. However, qualitative responses indicated that travelling and home maintenance were the activities most likely to be discontinued after stroke, while civic activities and social life were severely reduced.

Some research has involved the assessment of rehabilitation programs. However, the results have been unclear and researchers have been unable to find consistent evidence of specific improvements related to the programs. This may be because these programs did not incorporate or respond to the identification of salient psychosocial issues for the population of persons who experienced stroke. For example, Friedland and McColl (1989) acknowledged that "poor psychological outcome may be attributable

to the stressful life events that accompany [stroke]" (p. 55), and evaluated an intervention program, developed from the hypothesis that improved social support would act as a buffer for the stressful accompaniments of stroke. However, the authors identified several problems with the program. For example, they were unable to assess aphasic stroke survivors [sic] because the assessment instruments were strongly language based, there were problems for individuals with little or no pre-morbid social network, and the social network offered by the occupational therapist was not seen to replace or replicate the effect of long-standing interpersonal relationships. In a study purported to examine psychosocial predictors of stroke outcomes, Colantonio, Kasl, Ostfeld and Berkman (1993) examined aspects of social support and depression in relation to limitation of physical functioning following stroke. They found that larger social networks were associated with lower risk of institutionalisation. This study was also limited in that it accessed a sample of participants who were over 65 years of age, and focused on a very limited number of psychosocial factors (basically, social support, and depression). Teasdale, Christensen and Pinner (1993) reviewed the outcomes of rehabilitation for cranial trauma and stroke patients, but were inconclusive in finding program related recovery.

Koivisto, Viinamaki, and Riekkinen (1993) responded to findings that depression is the commonest psychiatric reaction after stroke, and assessed the correlation of rehabilitation outcomes and depression in 246

stroke patients. They concluded that diagnosis and treatment of post-stroke depression is essential because of the potential negative impact of depression on rehabilitation outcome. However, they failed to identify any of the psychosocial factors that may contribute to such depression.

Finger (1993) discussed the prevention, assessment and treatment of sexual dysfunction following stroke, and noted the myriad of psychosocial sequelae of stroke, particularly those relating to self-confidence and self-esteem. However, Finger's study is limited in that it examines sexual dysfunction in isolation from other ramifications of the disease.

Clearly, research into the psychological aspects of stroke is limited. The little research completed has focused on specific psychosocial issues, or involved the evaluation of existing rehabilitation programs and the outcomes of such programs have been unclear.

Disease Specific Research

Disease-specific research is evident in relation to many diseases other than those of interest in the present study. For example, Henderson (1997) focussed on the psychosocial adjustment of cancer survivors (sic) and identified areas of difficulty in learning to live with chronic illness. This research proposed counselling interventions in response to the identified difficulties. While there has been useful information gained from such study, it is not generally applicable or comparable across diseases.

Evidence for Non-Disease Specific Research

The most recent literature in the field demonstrates an understanding of the growing need for a global, chronic illness perspective, and highlights the importance of psychosocial adaptation. Alonzo (2000) examined the post traumatic distress disorder potential of chronic disease. She noted the need for consideration of changes over the lifecourse that can be related to the disease itself, its symptoms and treatment, and co-morbid life events. In particular, she concluded that psychosocial strategies to cope with chronic illness develop over the life course. She noted the relevance of an accumulated burden of adversity that is faced by people with chronic illness. Results of a study by Turner and Kelly (2000) highlight the seriousness of the relationship between depression and chronic illness, postulating the possible expression of emotional distress through the development or exacerbation of physical symptoms.

Skenazy and Bigler (1985) examined psychological adjustment and neuropsychological performance of Type I diabetic patients. They concluded that the essential variable affecting adjustment was having a chronic illness rather than anything particularly associated with Diabetes. This highlights the importance of looking at issues in a non-disease specific fashion. In addition, Garrett (2001) noted that “regardless of the specific diagnosis, chronic illness may produce uncertainty and anxiety, threatening the sense of self (p. 2)”. In particular, the impact on psychosocial well-being

in adults who usually have an established lifestyle and sense of who they are is critical. While this has been evidenced by increasing interest in, and acknowledgment of, the importance of psychosocial aspects of chronic illness in the literature over the last decade, this has not focussed especially on the needs of those facing adult onset chronic illness, except in a disease specific fashion. Even then, the research has not effectively compared and contrasted different chronic illness groups.

Conclusions

Review of the extensive array of research related to chronic illness leaves more questions unanswered than answered. It can be seen that there is a paucity of research addressing the issues of adults with chronic illness, in particular adult-onset chronic illness. Moreover, research which focuses on the experiences of people with chronic illness, from their own perspective, is virtually non-existent. In addition, notably, a global understanding of chronic illness, as well as comparisons between illnesses is lacking. Clearly, an approach that allows an overview as well as delineation of subgroups is vital in improving understanding of, and response to, chronic illness.

CHAPTER 4

METHODOLOGY FROM THE THEORY OF REASONED ACTION

Rationale for Application

This research is largely interested in determining attitude as a precursor to the attainment of outcomes (life goals) and the performance of behaviours which impact on health status and perceived quality of life of people with chronic illness. It is a contention of this thesis that behaviours manifest attitudes, and attitude influences, both directly and indirectly, health outcomes. In the present study, the determination of beliefs and attitudes about chronic illness in general, and the specific diseases in particular, are of interest. This is related to the belief that attitude impacts on behaviours and also directly and indirectly on health outcome.

Underlying Assumptions of the Theory

In order to ascertain these beliefs, the study proceeds according to the procedures identified by Fishbein and Ajzen (1980) and in accordance with the Theory of Reasoned Action (TRA). They noted that beliefs about the world and the people in it, as well as beliefs about self, underlie a person's attitude. According to the theory, two components act to predict behaviour or outcomes. The first is a set of *attitudinal beliefs* reflecting the ideas that the individual personally holds. The second is a set of *normative*

beliefs, reflecting the influence of other people. The beliefs that individuals hold about themselves and their environment are used to develop an understanding of the world, and to cope with the world with which they are faced. Although the Theory of Reasoned Action model is commonly known to be applied to the prediction of behaviour, it is also applicable to the attainment of outcomes (Ajzen & Fishbein, 1980). The theory explains that we develop beliefs about an object (or outcome) dependent on the association of positive or negative attributes to that object. We may form many different beliefs about the same object, in differing ways. We may observe characteristics directly, we may accept information from others, or we may make inferences about the object. Nonetheless, by adulthood, most people will have developed certain beliefs about a number of objects or outcomes. This refers to life outcomes in general, rather than to particular health outcomes.

There may be a large number of beliefs held about any particular object or outcome but, Ajzen and Fishbein theorised, that only a small number of these beliefs can be attended to at any given time. Thus, they theorised that these beliefs that come to mind before others are more salient and are, thus, the immediate determinants of attitude. These are referred to as *salient beliefs*. This leads to the understanding that in order to know why a person holds a particular attitude toward an object, we must assess the salient beliefs that are held in relation to the object.

Similarly, the opinions of many people may be known to the individual, about a particular object. However, those people whose opinion comes to mind before any others, are seen as more salient. It is theorised that these are the people the individual is more likely to refer to. These are called the *normative referents*.

A person's attitude is proposed to be a function of the perceived consequences related to behaviour or issue (*salient beliefs*) and an evaluation of those consequences (*outcome evaluation*). A person's subjective norm is proposed to be a function of those people perceived as important in relation to the object (*normative referents*), and the degree to which the individual is motivated to comply with the wishes of those people (*motivation to comply*).

Modal Salient Beliefs

In order to compare the beliefs of different individuals and to analyse these quantitatively, the theory provides a process for the identification of a set of beliefs that are salient in a given population. These are referred to as *modal salient beliefs*. In order to determine these modal salient beliefs, the process is similar to that used when eliciting salient beliefs from individuals. A sample is asked to list the advantages and disadvantages, and anything else, they associate with the object or outcome. These individually elicited beliefs are then grouped via content analysis, and frequency of elicitation is counted. The belief groups are then listed in order

of frequency. The rule of thumb, of a 75% cutoff criterion is then applied. That is, those belief groups which account for 75% of the total number of elicited beliefs, are taken as the modal salient beliefs. This was the process used in the present study

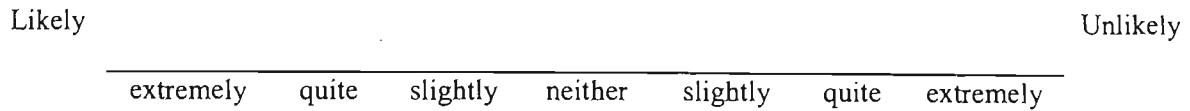
The Research Process of the Present Study

The research proceeds in stages. The first two stages are consistent with the model of the TRA. This model has been used extensively to examine belief structures associated with various behavioural domains and physical conditions. It remains dominant in the attitude-behaviour literature, and “inevitably it serves as the standard to which new ideas and theories are compared” (Olsen & Zanna, 1993, p. 131). The process is such that the resulting questionnaire can only include dimensions that arise from the elicitation data.

Firstly, participants are interviewed and the results analysed to determine modal salient beliefs and normative referents. The elicited salient beliefs then formed the basis for items reflecting attitudes on the questionnaire. The elicited normative referents formed the basis for items pertaining to subjective norm on the questionnaire². Each question was rated on a seven point bipolar scale from extremely likely to extremely unlikely, or from extremely good to extremely bad. Participants were asked to respond in respect to their illness. For example, the relevance of a specific

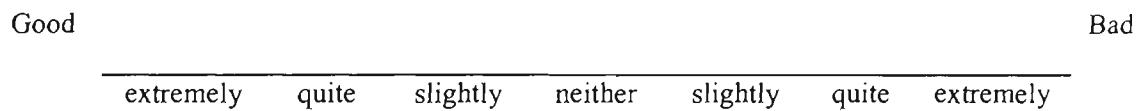
belief with respect to a consequence or outcome was measured according to the participant's response to the following question:

I will be frustrated:



The participant's evaluation of this belief was measured according to the response to the following question:

Being frustrated is:



When the developed questionnaire is distributed, respondents then have the opportunity to express either positive or negative attitudes to each of the salient beliefs.

Secondly, the developed questionnaire is piloted by distributing to participants for completion, as a form of validity checking. The data collected through the piloting of the questionnaire is then checked for reliability. The discriminant capabilities of the scale are also analysed. The results of these analyses are used to guide the finalising of the questionnaire.

² In the context of this work, it should be noted that salient referents are not necessarily social supports. Rather, they are those whose opinion is pertinent to the individual.

CHAPTER 5

STAGE ONE

ELICITATION STUDY

Introduction

This chapter describes the procedure of eliciting the salient beliefs of people with chronic illness. This stage is consistent with the process of the Theory of Reasoned Action (Ajzen & Fishbein, 1980) and is qualitative in nature. This is the first step in the process of developing a scale, which will reflect the issues that are most relevant to participants, and which will incorporate the language of participants. It is in this stage that the participants are informants, and it is in this stage that the researcher is first aware of the relevant issues and the language used to describe them.

All participants were 18 years of age or over and to have been diagnosed with one of the three chronic illnesses: Diabetes, Arthritis, or Stroke. Participants included inpatients at a private rehabilitation hospital, outpatient clinic attenders at a large public hospital, and disease-specific support group members. After discussion and collaboration with medical associates from the participating hospitals, participation was limited to include only those arthritis patients with inflammatory forms of the disease, non-aphasic stroke patients, and only Type II diabetes patients. Participants

were screened for current drug therapy due to the potential prescription of mood altering medication, and the prescription of steroids in some cases of arthritis. Participants currently taking anti-depressant or depressant drugs were excluded from the sample. In addition, the dosage levels of drugs prescribed as smooth-muscle relaxants were ascertained due to the potential mood-altering effects of some of these drugs (e.g., Valium).

The diabetes group consisted only of those participants who were diagnosed with Type II Diabetes. This means that there is onset of the disease after maturity. This was necessary due to the research interest in coping with chronic illness, which has an onset after the development of a sense of self. It is likely that different issues arise when an illness or condition develops in childhood. This is beyond the scope of the current research. Participants in the stroke group were included only if they were non-aphasic.

Several participants were accessed after the researcher made presentations at meetings of their support groups. This was done in order to access some persons who did not participate in hospital programs, or who were not currently involved in the hospital context. A private rehabilitation hospital was able to provide a number of participants. The researcher was advised of the admission of suitable participants. After the researcher had contacted the potential participant and secured permission, the participant's medical records were screened to determine and confirm diagnosis and

demographic details.

The participating large public hospital required a senior medical officer to liaise with the researcher in each department accessed for the purpose of the research. This was arranged and discussions within each department proceeded to develop protocols and working relationships.

(Appendix A)

Participants were able to have a third party present if they indicated their desire do so. A small number was accompanied by relatives during the interview. One participant, who had English as a second language, requested clarification of some words she wished to use in her reply, this was provided by her daughter. Similarly, some participants required assistance to complete the questionnaire during pilot and final stages of the research. This was provided by the researcher or by their usual carer, who was instructed to read the question aloud and then to mark the questionnaire to correspond to the answer indicated by the participant.

Method

Participants

Participants ($n = 62$) who all met the research inclusion criteria, included inpatients at a private rehabilitation hospital, inpatients and clinic attenders at a large public hospital and participants in a local self-help/support group in Melbourne, Australia. Participants ranged in age from 36-90 years and included 16 who had experienced stroke (10 male, 6

female); 22 who experienced Arthritis (6 male, 16 female) and 24 who experienced Diabetes (14 male, 10 female).

Instrument

Based on the process described by Fishbein and Azjen (1980), salient beliefs and attitudes were elicited by the use of six open-ended questions. Participants could, therefore, include any issues or attitudes. These could be manifested in several ways (e.g., humour, spirituality). Participants had the opportunity to express either positive or negative attitudes to each of their salient beliefs. Patton (1980) highlighted the use of open ended questioning as a means of finding out “what peoples’ lives, experiences, and interactions mean to them in their own terms” (p. 22).

The questions used in the elicitation interviews are listed below:

1. What do you see as the advantages associated with your illness today?
2. What do you see as the disadvantages associated with your illness today?
3. Is there anything else you associate with your illness today?
4. Are there any groups or people who are important to you, who are advantaged by your illness as it is today?
5. Are there any groups or people who are important to you, who are disadvantaged by your illness as it is today?
6. Are there any other groups or people who come to mind when you think about your illness today?

Participants’ responses to these questions were recorded on a standardised

response sheet, in order to maintain consistency over interviews. (Appendix B)

Procedure

Participants were interviewed to identify salient beliefs of people with chronic illness. This elicitation involved interviewing participants with a series of broadly based, open-ended questions. Participants were asked to list the advantages, disadvantages, and general ideas they held in relation to their illness (salient beliefs). In a similar way, participants provided information regarding people or groups in their lives they thought of in regard to their illness (salient referents).

At the public hospital, the researcher attended regular outpatient clinics for each of the diseases of interest. Potential participants were identified by the Registrar who set aside their medical files in case they agreed to participate. Doctors also explained the presence of the researcher to patients, as they were examined. The potential participant was then called to a separate interview room where written authorities (Appendix C) were signed, information sheets were distributed to participants and elicitation interviews proceeded, if they agreed to take part.

Participants were able to have a third party present. A small number was accompanied by relatives during interview.

Interviews proceeded, within each illness group, until patterns and themes emerge up to the point of saturation. After general discussion,

introduction and explanation, the formal interview lasted approximately 20 minutes.

Analysis

In accordance with the procedures described in by Fishbein and Ajzen (1980) interview responses were sorted into patterns and themes in order to determine the belief groupings elicited. Elicited beliefs, and frequency of those beliefs, were estimated and then listed in descending order. This procedure was followed in each of the three illness groups separately and then again with the elicited themes from the three groups pooled into one. This was done in order to provide a preliminary exploration trends regarding illness specificity and generalisability across groups. To identify salient beliefs and salient referents, a content analysis was performed (Appendix D)³, with a 75% cut-off rate used to determine salient issues. This appendix also shows frequencies of each response by disease group.

In the first instance, this was completed for each of the three illness groups and resulted in identifying several beliefs commonly held by all participants, as well as several beliefs unique to each illness group. These beliefs then formed the basis of a closed-format questionnaire.

Results

Results indicated support for anticipated trends. Firstly, that there

will be behavioural and normative beliefs which are found to be consistently salient across all the illness groups, and secondly, that there will be differences between groups in regard to specific behavioural and normative beliefs. This is shown in Table 1 below.

Table 1
Salient Issues Across the Three Illness Groups

	Diabetes	Arthritis	Stroke
Changes to diet, smoking, drinking habits	✓		✓
Coping with symptoms	✓	✓	✓
Stoicism	✓	✓	✓
Work/employment	✓	✓	
Can't do something like used to do or want to do	✓	✓	✓
Increased emotionality	✓		
Worry about general health	✓		
Worry about dying	✓		
Communicating with significant others	✓		
Knowledge of illness/disease	✓	✓	✓
Depressed	✓	✓	
Decreased power/control	✓	✓	
Changed social life	✓		
Mobility, getting around		✓	✓
Positive changes to me		✓	✓
Have to rely on others		✓	
Frustration		✓	✓
Accommodate illness,		✓	✓

³ Similar content analyses for each disease separately can be seen in appendix E.

know limitations			
Hospitals, doctors		✓	✓
Social support		✓	
Changes to self-concept		✓	✓
Concern about future			✓
It was a shock, hard to accept			✓

It can be seen in Table 1 that there are clear differences in each illness group in regard to salient issues. Commonly held salient issues were coping with symptoms, remaining stoic, being unable to do something like used to do or want to do, knowledge of illness or disease. (Further detail in regard to salient beliefs and referents for each illness group can be seen in Appendix E.)

In the second instance, salient beliefs and referents were determined for the sample as a whole. That is, by combining the elicited beliefs and referents over the entire sample and considering them as a group representing persons with a chronic illness or condition, and applying the procedure of TRA to determine salient issues. Combining the elicited beliefs from the three illness groups and determining 75% of the total number of salient beliefs elicited provided for 18 salient beliefs and five normative referents.

The selected salient beliefs were:

1. I will have to cope with symptoms.
2. I will be unable to do something like I used to do or want to do.

3. I will be unable to get around as easily or as much as I want.
4. I will just put up with it or make the best of things.
5. I would like more information.
6. I will be a better person.
7. I have to be aware of limitations and work things out around my illness.
8. I will not be the same person I used to be.
9. I will not be able to work.
10. I will have to rely on other people.
11. I will be frustrated.
12. I will have less power and control in my life.
13. I will be taken care of by doctors and the hospital.
14. I will be depressed.
15. I will have to change my diet, smoking or drinking habits.
16. I am worried about the future.
17. I will have the social support of people around me.
18. I will have to cope with my medical regime and medical technology.

The selected salient referents were:

1. Spouse/partner
2. Friends
3. Daughter/daughter-in-law

4. Children
5. Medical and allied health practitioners

Discussion

Several of the issues raised in the literature are reflected in the findings of this stage of the research. For example, some of the psychosocial effects of chronic illness suggested by Kohler, et al. (1990), included changes to self-image and fear. These issues are in line with the identified salient belief of : I will not be the same person I used to be, and, I am worried about the future.

Detailed examination of the salient issues identified for each disease group as shown in Table 1 also show some agreement with previous findings. Hess, et. al. (1987), described issues for diabetes patients as including adherence to the treatment regimen, issues of control, problems with relationships, financial concerns, and reduced abilities to work, travel and be active. These may be evidenced in the current study as issues around work/employment, communicating with others, decreased power and control and changed social life.

In regard to rheumatoid arthritis, Krol, et al. (1992), identified areas of concern around a loss of independence, social withdrawal, loss of employment, reduced leisure activities and financial problems. Some of these are reflected in the current study in the identified issues as relying on others, and issues about work/employment.

In regard to stroke, Kettle and Chamberlain (1988) identified loss of mobility, transport problems associated with not driving a car, relying on other people, limited leisure time activities and depression. In the current study these correspond to not being able to something like I used to do or want to do, and issues of mobility/getting around.

It is interesting to note that, when the data from each chronic illness group was pooled, the salient beliefs identified, more broadly reflected the issues described by past research. For example, the issues of self-image and fear discussed by Kohler, et al., (1990) in relation to chronic illness in general are identified. In addition, while still identifying the issues relating to diabetes, arthritis and stroke which were found in the examination of issues for each illness separately, the pooled results identified additional issues which were discussed in the literature. These were in relation to treatment regimen in the diabetes group (as discussed by Hess, et al., 1987), reduced leisure activities in the arthritis group (as discussed by Krol, et al.), and relying on others, and being depressed in the stroke group (as discussed by Kettle & Chamberlain, 1988).

CHAPTER 6

STAGE TWO

PILOTING OF SCALE

In the elicitation stage (Stage One), a series of open-ended, semi-structured interviews were used to determine the beliefs of participants in three illness groups. The results of these interviews were then pooled and re-examined to determine the modal salient beliefs of people with chronic illness, as represented by the three illness groups selected. This resulted in finding 18 salient beliefs and five normative referents (representing perceived social support). These then formed the basis of items on the questionnaire, incorporating an *attitude* scale and a *social/normative referent* scale. Stage Two involves piloting of those scales.

This stage of the research focussed on issues regarding the development of the scale, while also checking some of the overall hypotheses of the thesis. The hypotheses to be tested in this stage of the research were:

1. The instrument will show high internal consistency.
2. Instrument will correctly classify/discriminate between the participants by identifying salient issues that are both common and

unique to each illness group.

3. The instrument will demonstrate statistical reliability.
4. There will be a positive relationship between the measure of mobility and attitude.
5. There will be differences in attitude across different levels of mobility.

Method

Participants

All participants were 18 years of age or over and to have been diagnosed with one of the three chronic illnesses: Diabetes, Arthritis, or Stroke. Participants included inpatients at a private rehabilitation hospital, outpatient clinic attenders at a large public hospital, and disease-specific support group members. After discussion and collaboration with medical associates from the participating hospitals, participation was limited to include only those arthritis patients with inflammatory forms of the disease, non-aphasic stroke patients, and only Type II diabetes patients. Participants were screened for current drug therapy due to the potential prescription of mood altering medication, and the prescription of steroids in some cases of arthritis. Participants currently taking anti-depressant or depressant drugs were excluded from the sample. In addition, the dosage levels of drugs prescribed as smooth-muscle relaxants were ascertained due to the potential mood-altering effects of some of these drugs (e.g., Valium).

The diabetes group consisted only of those participants who were

diagnosed with Type II Diabetes. This means that there is onset of the disease after maturity. This was necessary due to the research interest in coping with chronic illness, which has an onset after the development of a sense of self. It is likely that different issues arise when an illness or condition develops in childhood. This is beyond the scope of the current research. Participants in the stroke group were included only if they were non-aphasic.

Participants (n= 74) were obtained through outpatient clinics at a large public hospital and a private rehabilitation hospital in Victoria, Australia. The sample consisted of 26 females (35.1%) and 48 males (64.9%) who ranged in age from 37 to 87 years ($M= 61.81$, $SD= 13.74$). All participants were taking some form of medication. Three chronic illness groups were represented: 24.3% (n= 18; 88.8% male, 11.2% female) of participants were diagnosed with diabetes, 48.6% (n= 36; 33.3% male, 66.7% female) with arthritis, and 27% (n= 20; 91.6% male, 8.4% female) with stroke. The duration of disease ranged from 0 years to 60 years ($M= 16.84$, $SD= 18.22$).

Questionnaire

The elicited salient beliefs from Study One, formed the basis for items assessing attitude on the questionnaire. The elicited salient referents formed the basis for items measuring perceived social support on the questionnaire. Each question was rated on a seven point bipolar scale from

extremely likely to extremely unlikely, or from extremely good to extremely bad. Several questions were phrased in the negative form to offset any response set, such as acquiescence (Bentler, et al., 1971). Participants were asked to respond in respect to their illness.

The pilot questionnaire consisted of 48 questions, designed to determine attitude and perceived social support. Participant's diagnosis, level of physical restriction, and other demographic details were requested in the first section of the questionnaire.

Procedure

Participants for the piloting phase were contacted within the hospital clinic on a personal basis, or by mail. Mailing took place in October 1996. Participants were asked to independently complete the questionnaire. Participants were mailed the questionnaire, and explanatory letter, consent form (Appendix F), and a reply paid envelope in which to return the completed questionnaire. The questionnaire was sent to all participants from stage one, as a reliability measure. This process is consistent with the work of Fishbein and Ajzen and is a recognised method of checking reliability of such a measure (Ajzen, 1988). The questionnaire was also completed by a number of new participants as a result of snowballing interest generated by communication with participants from Stage One.

Some participants required assistance to complete the questionnaire. This was provided by the researcher or by their usual carer, who was

instructed to read the question aloud and then to mark the questionnaire to correspond to the answer indicated by the participant.

One participant from stage one was deceased by the time of piloting and was, therefore, not included. All other participants from Stage One responded in Stage Two. There were 13 new participants in this stage. In total, 75 questionnaires were distributed, and 74 were completed and returned (98.6% response rate).

Data Preparation

Dependent variables

The dependent variables (attitude to life post-diagnosis and perceived social support) were measured by summing the products of the strength of a behavioural belief multiplied by the evaluation of the outcome of this behavioural belief. For example, a participant marked this scale as being *quite good*,

Being able to work is:

good	X	bad				
extremely	quite	Slightly	Neither	slightly	Quite	extremely

and marked the corresponding scale as *extremely unlikely*,

I will be able to work:

likely	X	unlikely				
extremely	quite	Slightly	Neither	slightly	quite	extremely

These responses are numerically coded as 2 and -3, respectively. The product of these is -6. This calculation is made for each pair of questions, based on each salient belief. The scores for all the salient beliefs are then summed, resulting in a score for *attitude*.

The same process is applied to the pairs of questions based on each of the five normative referents. The sum of these scores results in a measure of *perceived social support*.

Independent variables

The variable, mobility, was measured by summing the score for each variable, with the single variable driving a car reversed scored. Scores range from 5-25, with higher scores equating to less reliance on mobility aids and relatively better mobility. To enhance meaningfulness, these scores were then categorised into degrees of mobility: very high, high, medium, low and, very low. These categories were determined by score increments of 5 points.

Results

The reliability of each scale was tested with a Cronbach's alpha. The results indicated an alpha of 0.72 ($N= 74$) for attitude to life post-diagnosis, alpha of 0.64 for the perceived social support scale, and an alpha of 0.74 for the mobility scale.

The results of a one-way ANOVA testing for differences in attitude to life post-diagnosis by mobility, indicated that there was a significant overall

difference across groups, $F(3, 69) = 32.27, p < .001$. Post hoc Scheffe analysis indicated significant mean differences in attitude between high mobility ($M = -9.90, SD = 13.17$) and low mobility ($M = 30.75, SD = 2.88$), $p = 0.01$; high mobility and very low mobility ($M = -93.00, SD = 0.00$), $p < .001$; medium mobility ($M = 1.66, SD = 22.14$) and; very low mobility, $p < .001$; low mobility and very low mobility, $p < .001$.

The results of a one-way ANOVA testing for differences in perceived social support by diagnostic group, indicated that there was a significant overall difference across groups, $F(2, 63) = 17.39, p < .001$. Post hoc Scheffe analysis indicated significant mean differences in perceived social support between diabetes and arthritis ($p < .001$), diabetes and stroke ($p < .001$), and between stroke and diabetes ($p < .001$). The means and standard deviations for each diagnostic group are shown in Table 2.

Table 2
Means and Standard Deviations for Level of Normative Reference by Diagnostic Group

	<u>Diabetes</u>	<u>Arthritis</u>	<u>Stroke</u>
Mean	30.83	6.14	5.94
Standard Deviations	3.56	2.84	3.56
<i>n</i>	18	28	18

In order to test the discriminant validity of the scale, prediction of membership into the three diagnostic groups (diabetes, arthritis, and stroke) was determined by standard (direct) discriminant function analysis. Two discriminant functions were calculated, with a combined $\Lambda = 0.02$, $\chi^2 (36, N= 74) = 246.12, p = 0.000$. After removal of the first function, there was still highly discriminating power, $\Lambda = 0.28$, $\chi^2 (17, N= 74) = 79.05, p = 0.000$. The two functions accounted for 84.10% and 15.90% respectively, of the between group variability.

The first discriminant function maximally separated the stroke and arthritis groups and moderately separated the diabetes and arthritis groups. The second function best discriminated between the arthritis and diabetes groups, and moderately separated the arthritis and stroke groups, see Figure 2.

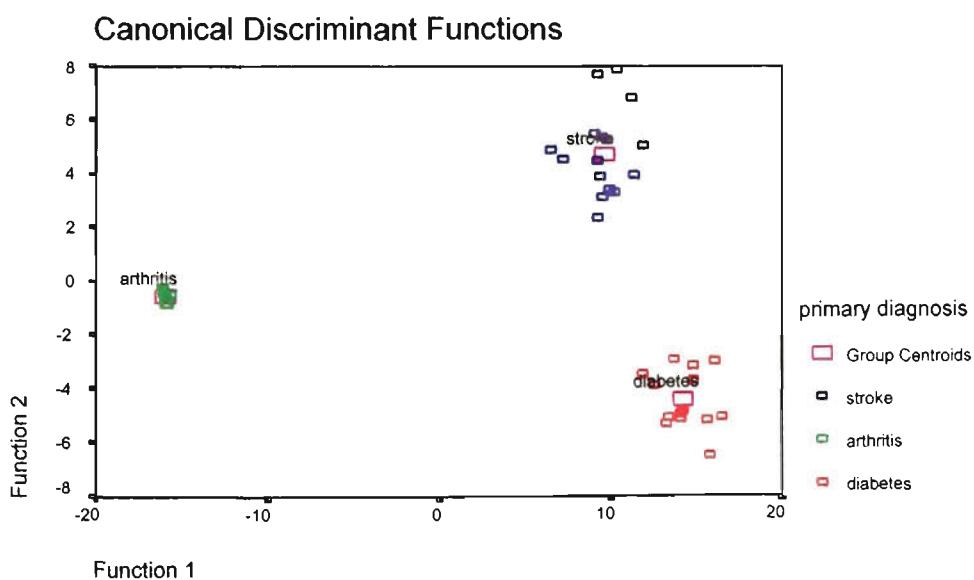


Figure 2: Plot of Three Group Centroids on Two Discriminant Functions from 18 Predictor Variables Using Pilot Data Set.

There was statistically significant discrimination among the three groups on nine predictor variables: I am not able to do something like I used to do or want to do; I am aware of my limitations and arranging things to accommodate my illness or condition: I am a different person to what I was before my illness or condition (change in self-concept); I have to rely on other people in some way; I am frustrated; I have less power and control in my life; I have been changed in some way that is an improvement to the way I was before my illness; I am depressed and; I have made changes to my diet, smoking or drinking habits.

The pooled within-group correlations between discriminating variables and canonical discriminant functions (structure coefficients) were used for interpreting the functions. Coefficients lower than 0.3 were not considered (Tabachnik & Fidell, 1989).

Evaluation of the structure matrix suggests that the three variables that best distinguished arthritis from stroke groups (function one) were; I am a different person to what I was before my illness or condition (change in self-concept); I am not able to do something like I used to do or want to do; I have made changes to my diet, smoking or drinking habits. The arthritis group reported a more negative change in self-concept ($M= -2.11$, $SD= 3.90$) than the stroke group ($M= 1.05$, $SD= 2.93$); were less able to participate in activities they liked ($M= -3.78$, $SD= 5.17$) than the stroke group ($M= 0.55$, $SD= 3.40$) and; greater change in dietary habits ($M= -1.11$, $SD= 3.17$) than

the stroke group ($M= -0.65$, $SD= 3.92$).

For the second discriminant function, the three predictor variables that separated arthritis from diabetes were; I have less power and control in my life; I am aware of my limitations and arrange things to accommodate my illness or condition and; I have been changed in some way that is an improvement to the way I was before my illness. The arthritis group reported more power and control in life ($M= -2.67$, $SD= 4.66$) than the diabetes group ($M= -4.39$, $SD= 1.72$); less changes in accommodating for illness ($M= 1.55$, $SD= 5.97$) than the diabetes group ($M= 1.83$, $SD= 2.66$).

Of the total sample, 98.6% of cases were correctly classified (Table 3).

Table 3
Discriminant Function Classification Results (N= 74) for Pilot Stage

<u>GROUP</u>	<u>n</u>	<u>PREDICTED GROUP MEMBERS</u>		
		<u>Arthritis</u>	<u>Diabetes</u>	<u>Stroke</u>
Arthritis	36	36 94.4%	---	---
Diabetes	18	1 5.6%	17 100%	
Stroke	20	---	---	20 100%

Discussion

With regard to the hypothesis that mobility will have a significant effect on attitudes to life post-diagnosis, the results indicated that there was a significant overall difference. Post hoc analyses indicated that the only comparisons that were not significant were participants in the high mobility and medium mobility groups as well as those in low mobility and medium mobility groups. These results provide support the findings of Kohler, et al., (1990) that deteriorating mobility was associated with hopelessness, and of Antler, et al., (1969) that patients' attitudes to the wheelchair became less positive as the physical impairment worsened. The results may also reflect the findings of Jensen (1991), that increased social problems were associated with physical disability.

The discriminant function analysis supports the validity of the 'Attitudes to Life Post-Diagnosis' scale as the three diagnostic groups were adequately discriminated. The variables that maximally separated the arthritis and stroke groups (factor one) were changes in self-concept, level of activity and dietary habits. The variables that maximally separated the arthritis and diabetes groups (factor two) were level of power and control, accommodating for illness constraints, and self-development as a result of being ill.

These results are in line with previous research (Koivisto, et al., 1993; Sullivan, 1978; Swift, et al., 1967), which found that people with

arthritis and with stroke experienced reduced self esteem. This may reflect in the discriminatory variable of self-concept. In noting difficulty with the experience of daily injections, Cleaver and Pallourios (1994), provided some explanation for the current results, which show the diabetes group making more accommodation in their lives, for their illness. However, as discussed earlier, previous studies have not been able to make comparisons between illness groups, and therefore, direct links between past studies and the present findings are not possible.

Cronbach's alpha coefficients for each scale indicated high reliability. The scales are important because they acknowledge the impact of psychosocial factors in chronic illness, and represent a more holistic view of illness.

Compilation of Final Questionnaire

In light of the results obtained with the pilot questionnaire, it was decided to distribute it in its entirety for the final phase. However, in order to gauge a measure of validity, the final questionnaire included a measure of Locus of control consisting of 18 questions taken from Wallston's Health Locus of Control Scale (Appendix G).

CHAPTER 7

MAIN STUDY

Introduction

This chapter firstly discusses the main study focusing upon the testing of the final scale - including the results of reliability and validity testing. Validity was tested by the inclusion of the Health Locus of Control Scale, in order to contrast attitude with both internal and external locus of control. In relation to scale development the hypotheses to be tested are :

1. The instrument will show high internal consistency.
2. The instrument will correctly classify/discriminate between the participants by identifying salient issues that are both common and unique to each illness group.
3. The instrument will demonstrate statistical reliability.
4. There will be an inverse relationship between attitude and external locus of control (validity check).
5. There will be a positive relationship between attitude and internal locus of control (validity check).
6. There will be a positive relationship between attitude and mobility.

Secondly, this chapter addresses the overall aims of the research by testing the hypotheses related to these aims, and the information to be

ascertained from the utilisation of the developed scale. The aims and hypotheses relating to this are:

Overall Aims

1. To assess psychological and social areas of concern and need for persons with chronic illness, as represented by the three diagnostic groups of interest.
2. To gauge a measure of physical mobility.
3. To develop a questionnaire to measure the psychosocial status of persons with chronic illness, resulting in an overall measure of attitude to life.

Overall Hypotheses

1. Because of the experience of chronic illness there will be behavioural and normative beliefs that are found to be consistently salient across all the disease groups.
2. There will be differences between the illness groups in regard to specific behavioural and normative beliefs.
3. There will be variation in overall measure of attitude to life dependent on the gauged level of mobility, with higher levels of mobility being related to more positive attitude.
4. As the use of *visible* mobility aids (walking stick, frame, wheelchair) increases, the measure of attitude to life will become more negative.

Participants

All participants were 18 years of age or over and to have been diagnosed with one of the three chronic illnesses: Diabetes, Arthritis, or Stroke. Participants included inpatients at a private rehabilitation hospital, outpatient clinic attenders at a large public hospital, and disease-specific support group members. After discussion and collaboration with medical associates from the participating hospitals, participation was limited to include only those arthritis patients with inflammatory forms of the disease, non-aphasic stroke patients, and only Type II diabetes patients. Participants were screened for current drug therapy due to the potential prescription of mood altering medication, and the prescription of steroids in some cases of arthritis. Participants currently taking anti-depressant or depressant drugs were excluded from the sample. In addition, the dosage levels of drugs prescribed as smooth-muscle relaxants were ascertained due to the potential mood-altering effects of some of these drugs (e.g., Valium).

The diabetes group consisted only of those participants who were diagnosed with Type II Diabetes. This means that there is onset of the disease after maturity. This was necessary due to the research interest in coping with chronic illness, which has an onset after the development of a sense of self. It is likely that different issues arise when an illness or condition develops in childhood. This is beyond the scope of the current research. Participants in the stroke group were included only if they were

non-aphasic.

Participants included 226 persons, combining those from both the pilot and final data collection stages of the research. The sample consisted of both females (46.3%) and males (53.7%) who ranged in age from 17 to 87 years ($M=60.09$, $SD= 14.21$). Three chronic illness groups were represented; 30.7% ($n= 67$) of participants were diagnosed with diabetes, 43.6% ($n=95$) with arthritis, and 17% ($n=37$) with stroke. All participants were taking some form of medication. Nineteen (8.7%) of the participants had multiple diagnoses and were excluded from analyses along with eight cases that were excluded due to missing data. The duration of disease ranged from less than one year to 81 years ($N=200$, $M=15.19$, $SD=15.73$).

In order to increase power and robustness of statistical analyses, it was decided to determine the appropriateness of combining data from the pilot study with data from the main study. Thus, power and robustness are increased by increasing sample size (Kaplan, 1987).

In order to examine the viability of combining data from the pilot study with data from the final stage distribution, the two sets of data were compared on pertinent measures. This was done using one-way analysis of variance, comparing pilot data and second set data on participants' age in years, age at first experience of symptoms, duration since onset of illness, overall measure of mobility, normative beliefs, and overall attitude to life post-diagnosis. No significant differences were found on any of these

variables (see Table 4), therefore, it is valid to combine the two data sets.

The finding of no significant difference between the data sets suggests that the null hypothesis can be accepted and the sets treated as equal.

Statistically, it can be assumed that the two samples are drawn from the same population (Kaplan, 1987).

Table 4
Analysis of Variance Between Pilot Sample and Second Stage Sample on Six Variables

	Pilot sample			Second stage sample			<i>F</i>	<i>p</i>
	<i>M</i>	<i>SD</i>	<i>N</i>	<i>M</i>	<i>SD</i>	<i>N</i>		
Age in Years	61.87	13.56	76	59.19	14.48	150	1.79	.18
First Symptoms	45.57	18.74	63	45.42	18.32	137	.003	.96
Duration	17.11	18.48	63	14.31	14.28	137	1.37	.24
Mobility	21.69	3.55	71	21.40	3.08	141	.36	.55
Normative Referents	11.02	14.53	66	8.55	13.83	124	1.32	.25
Attitude	-1.07	31.69	76	4.41	30.34	129	1.51	.22

Materials

The elicited salient beliefs from Study One, formed the basis for items assessing attitude on the questionnaire. The elicited salient referents formed the basis for items measuring social support on the questionnaire. Each question was rated on a seven point bipolar scale from “extremely likely” to “extremely unlikely”, or from “extremely good” to “extremely bad”. Several questions were phrased in the negative form to offset any response set, such as acquiescence (Bentler, et al., 1971). Participants were asked to respond in respect to their illness.

The final questionnaire, incorporating the attitude to life scale, and the perceived social support scale, consisted of 48 questions, plus 18 questions comprising Wallston's Health Locus of Control Scale. Participant's diagnosis, level of physical restriction (the mobility scale), and other demographic details were requested in the first section of the questionnaire.

Scale Development

In order to achieve this purpose, the research first identified salient beliefs and normative referents that were common to all three diagnostic groups. Those beliefs and referents, which were unique to each diagnostic group, were also identified. The salient beliefs, which were common to all diagnostic groups, are detailed in Chapter Five. These salient beliefs and referents were then used as a basis for items on the scale. Each question was

rated a seven point bipolar scale. Responses were numerically coded from -3 to +3 before data analysis. The variables *attitude* (to life post-diagnosis) and *normative referents* were determined by summing the products of the strength of each behavioural belief or normative referent multiplied by the evaluation of the outcome of this behavioural belief or normative referent.

Mobility

In consideration of previous research in regard to the effect of mobility on attitude, an overall measure of mobility was calculated from all five of the separate measures of driving a car, using a walking stick, using a walking frame, being in a wheelchair or scooter, and being bed bound. Each of these measures of mobility was scored on a five point scale from 'never' to 'always'. All items other than that of driving a car were reverse scored since 'never' using a walking stick, a walking frame, a wheelchair or scooter, and being bed bound, are clearly more positive than 'always'. Thus items were scored least positive for 'always' and most positive for 'never'. The item for driving a car was scored least positive for 'never' and most positive for 'always'. Overall scores on all measured dimensions of mobility were then summed to create a variable representing a measure of mobility. Scores range from 5-25, with higher scores equating to less reliance on mobility aids and relatively better mobility.

Locus of Control

The Multidimensional Health Locus of Control Scale (Wallston, et al., 1978), provides measures of *internality* (the extent to which an individual believes the locus of control for health is internal to them), *Chance* (the belief in chance or external factors in determining health outcome, and *powerful others* (belief that powerful others, particularly health professionals, have control over one's health (Weinman, Wright & Johnston, 1995). The scale consists of 18 items. Each item is responded to on a six point scale from 1-6, from strongly disagree to strongly agree. The Internal Health locus of Control (IHLC) was computed by adding scores on items 1, 6, 8, 12, 13 and 17. The Chance (external) Health Locus of Control (CHLC) was computed by adding scores on items 2, 4, 9, 11, 15 and 16. The Powerful others Health Locus of Control was computed by adding scores on items 3, 5, 7, 10, 14 and 18. The alpha reliabilities for Waldron's Health Locus of Control Scale were reported to range from 0.67 to 0.76.

Procedure

Participants for the final phase were contacted by mail. Mailing occurred in two waves, and took place in November and December 2000. Potential participants were sourced through review of hospital records of clinic attenders. Potential participants were mailed an explanatory letter requesting their participation in the research, the questionnaire, consent form (Appendix H), and reply paid envelope in which to return the

completed questionnaire. Participants were able to contact the researcher by telephone if they had any questions or concerns. Participants were asked to independently complete the questionnaire.

Some participants telephoned to clarify their eligibility to participate or to clarify some items in the questionnaire. Some participants required assistance to complete the questionnaire. This was provided by their usual carer, who was instructed read the question aloud and then to mark the questionnaire to correspond to the answer indicated by the participant. Four hundred questionnaires were mailed. Twenty-five were returned, marked wrong address, and eight were unusable due to inappropriate diagnoses. The usable response rate was approximately 60%.

Analysis and Results

The reliability of each scale was tested using Cronbach's alpha. The alpha for attitude to life post-diagnosis was 0.67 ($N=205$). The alpha for the perceived social support scale was 0.75 and for the mobility scale was 0.589. Reliability of the entire scale over 48 items was 0.61. The correlation between external locus of control and overall attitude to life post-diagnosis was -0.203 , with $p = 0.026$ ($N=121^4$). The correlation between internal locus of control and attitude to life post-diagnosis was 0.304 , $p < .001$ ($N=195$). Correlations of the estimate of overall attitude to the measure of overall

⁴ The low N in this analysis was due to missing data.

mobility and the five separate components of mobility, over the entire sample are shown in Table 5.

Table 5
Correlations of Attitude with Mobility and the Components of Mobility Over the Entire Sample

<u>Attitude</u>						
<u>Mobility</u>	<u>Car</u>	<u>Stick</u>	<u>Frame</u>	<u>Chair</u>	<u>Bed</u>	
.297**	.137	-.138	-.282**	-.359**	-.278**	
p	.000	.053	.052	.000	.000	.000
N	195	200	199	197	197	196

**significant at 0.01 level (2-tailed)

A significant positive correlation was found between the estimate of overall attitude and the measure of overall mobility. Significant negative correlations were found between the estimate of overall attitude and use of a walking frame, wheelchair or scooter, and being bed bound. There was a negative correlation between attitude and using a walking stick but this did not quite reach a level of significance. Similarly, there was a positive correlation between attitude and driving a car, which did not reach a level of statistical significance.

In order to assess differences in attitude between diagnostic groups, an analysis of variance was conducted. The measure of overall attitude ranged from -93 to 104 ($N= 199$). Analysis of variance for attitude showed a significant difference between diagnostic groups ($F = (2, 196) 4.74, p$

=.003). Means and standard deviations for each disease group are shown in

Table 6.

Table 6
Means and Standard Deviations of Attitude for Each Diagnostic Group

	<u>Diabetes</u>	<u>Arthritis</u>	<u>Stroke</u>
Mean	8.29	-6.45	5.94
Standard Deviation	27.68	32.49	31.80
N	62	85	34

Post hoc analysis indicated significant difference between diabetes and arthritis ($p = .040$), with the diabetes group reporting a more positive attitude. The stroke group also reported a positive attitude. The arthritis group were the only diagnostic group to report a negative attitude.

The results of a one-way analysis of variance testing for differences in perceived social support by diagnostic group, indicated there was a significant overall difference across groups, $F(3, 178)=4.90, p=.003$. Post hoc scheffe analysis indicated significant mean differences in perceived social support between diabetes and arthritis ($p=.003$). The means and standard deviations for each diagnostic group are shown in Table 7.

Table 7
Means and Standard Deviations for Perceived Social Support by Diagnostic Group

	<u>Diabetes</u>	<u>Arthritis</u>	<u>Stroke</u>
Mean	14.42	5.31	8.67
Standard Deviation	16.50	11.67	13.44
N	57	75	33

⁵

Standard regression analyses was completed in order to assess the effect of mobility on attitude and on the components of mobility. Regression analysis (Table 8) showed overall mobility to be a significant predictor of the estimate of overall attitude, as were all the separate components of the mobility measure ($p < .001$). In consideration of the reverse scoring of mobility items these results suggest that more positive attitude is associated with increasing ability to drive a car, and that more negative attitude is associated with increasing use of the various mobility aides and with being bed bound.

⁵ Means and standard deviations of all attitude items and normative referents can be seen in appendix I.

Table 8
Regression of Attitude on Mobility and the Separate Components of Mobility Over Entire Sample

	β	t	p
Mobility	.29	4.325	.000
Car	2.42	6.188	.000
Stick	-1.71	-6.040	.000
Frame	-1.23	-6.028	.000
Chair	-1.21	-6.976	.000
Bed	-1.41	-6.424	.000

R for regression for overall mobility measure was significantly different from zero, $F(1,194) = 18.71, p < .000$. R for regression for components was significantly different from zero, $F(6,194) = 13.274, p < .000$. All variables contributed significantly to the regression. Altogether 28% (adjusted R square = .275) of the variability in attitude was predicted by knowing scores on these independent variables.

In order to test the discriminant validity of the scale, prediction of membership into the three diagnostic groups (diabetes, arthritis, stroke) was determined by standard (direct) discriminant function analysis. Evaluation of linearity, normality, multicollinearity, and homogeneity of variance-covariance matrices revealed no threat to multivariate analysis.

Two discriminant functions were calculated, with a combined $\Lambda=0.41$, ($\chi^2: (48, N= 178)= 130.25, p= 0.000$). After removal of the first function, there was still high discriminating power, $\Lambda= 0.73$, ($\chi^2: (23, N= 178)=45.32, p= 0.004$). The two functions accounted for 65.5% and 31.5% respectively, of the between group variability. The first discriminant function maximally separated between arthritis and diabetes and moderately separated between diabetes and stroke. The second discriminant function maximally separated between Diabetes and stroke and moderately separated between arthritis and diabetes (Figure 3).

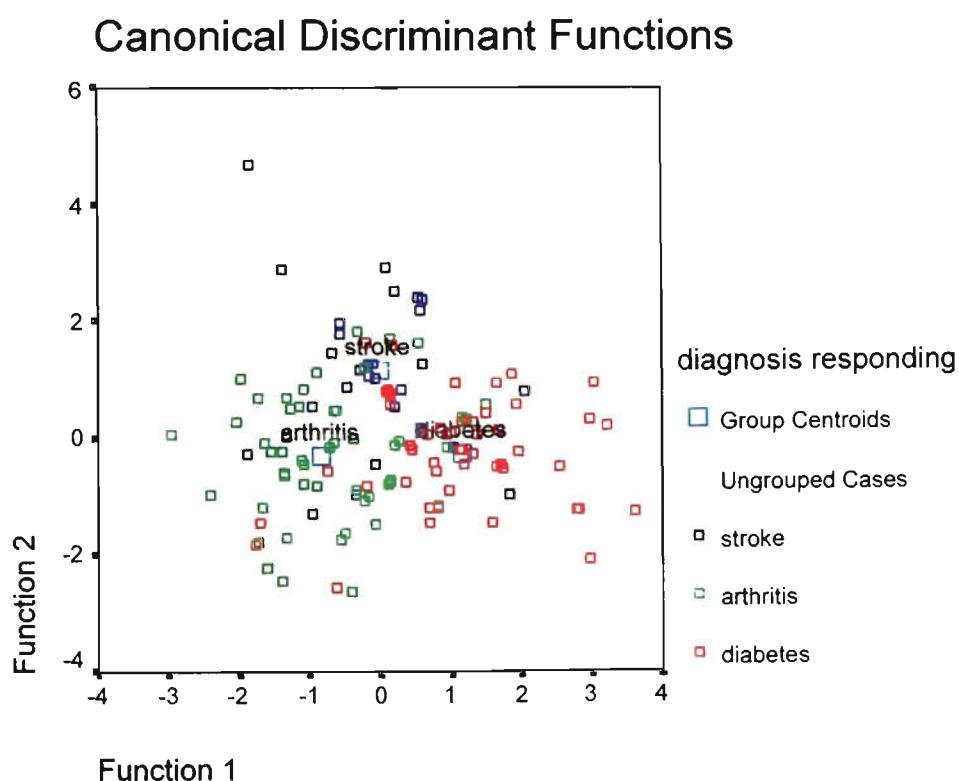


Figure 3: Plot of Three Group Centroids on Two Discriminant Functions from Predictor Variables Related to Attitude and Normative Referents.

There was statistically significant discrimination among the three groups on nine predictor variables including the normative referents (perceived providers of social support) daughter/daughter-in-law, medical and allied health personnel, and siblings, and the attitudinal components of coping with symptoms, not being able to do what I used to do or want to do, changed self-concept, being reliant on others, being frustrated and having reduced self-efficacy. The pooled within-group correlations between discriminating variables and canonical discriminant functions (structure coefficients) were used for interpreting the functions.

Evaluation of the structure matrix suggests that the three variables that best distinguished arthritis from diabetes groups (function one) were not doing what I used to do or want to do, being reliant on others, and seeing siblings as normative referents. Means and standard deviations for the two groups on these variables are seen in Table 9.

Table 9
Means and Standard Deviations on Three Discriminating Variables for Arthritis and Diabetes Groups for the First Discriminant Function

	<u>Arthritis</u>		<u>Diabetes</u>	
	<u>M</u>	<u>sd</u>	<u>M</u>	<u>sd</u>
Not doing what I want	-4.19	4.27	-7.41E-02	4.17
Being reliant on others	-3.18	4.30	-1.19	4.03
Siblings	0.15	3.38	3.19	4.39

For the second discriminant function, the three predictor variables that best separated diabetes from stroke were being frustrated, reduced self-efficacy, and having a changed self-concept. Means and standard deviations for the two groups on these variables are seen in Table 10. (Structure correlations for each dependent variable in the discriminant function analysis are presented in Appendix J.)

Table 10
Means and Standard Deviations on Three Discriminating Variables for Arthritis and Diabetes Groups for the Second Discriminant Function

	<u>Stroke</u>		<u>Diabetes</u>	
	<i>M</i>	<i>sd</i>	<i>M</i>	<i>Sd</i>
Being frustrated	0.65	4.85	-2.98	4.44
Reduced self-efficacy	0.62	5.15	-2.59	3.79
Changed self concept	5.88E-02	3.88	-0.80	4.31

Of the total sample, 79.4% of cases were correctly classified (Table 11). The highest percentage correctly classified was the arthritis Group. Using manual scanning of data, those participants with multiple diagnoses were determined to be 50% with diabetes and arthritis, 16.6% with diabetes and stroke, 11.1% with arthritis and stroke, and 11.1% with all three disease

conditions. Eleven point one percent did not report their diagnosis.

Table 11
Discriminant Function Classification Results *N=178*

<u>Diagnostic Group</u>	<u>Cases</u>	<u>Predicted group membership</u>		
		<u>Diabetes</u>	<u>Arthritis</u>	<u>Stroke</u>
<u>Diabetes</u>	54	43 79.6%	6 11.1%	5 9.3%
<u>Arthritis</u>	72	5 6.9%	63 87.5%	4 5.6%
<u>Stroke</u>	34	5 14.7%	8 23.5%	21 61.8%
<u>Multiple Diagnosis</u>	18	8 44.4%	7 38.9%	3 16.7%

In exploring the properties of the resultant values, analysis of variance (2×4 , gender \times diagnosis) showed that diagnosis was significant ($\lambda = 0.420$, $p < 0.0001$). Gender was not significant. Nor was the diagnosis/gender interaction. Further multivariate analysis of variance showed age functioning as a co-variate, but still not affecting gender or the diagnosis/gender interaction effect. Table 12 shows the results of this analysis of variance.

Table 12
Analysis Of Variance Results

Gender Of Participant	Primary Diagnosis	Mean	Std. Deviation	N	F	p
Male	Diabetes	9.88	24.56	44		
	Arthritis	-4.00	14.16	27		
	Stroke	3.74	32.33	31		
	Multiple	12.38	31.28	8		
	Total	4.93	25.89	110		
Female	Diabetes	4.39	34.65	18		
	Arthritis	-7.59	38.21	58		
	Stroke	28.67	12.34	3		
	Multiple	20.80	19.88	10		
	Total	-.75	36.60	89		
Total	Diabetes	8.29	27.68	62		
	Arthritis	-6.45	32.49	85		
	Stroke	5.94	31.80	34		
	Multiple	17.06	25.11	18		
	Total	2.39	31.19	199		
					2.427	.021
					.880	.349
					4.228	.006
					.941	.422
*Diagnosis						

To empirically examine the nature of the variables, a factor analysis was conducted, theoretically forcing to two factors and using a principal component analysis with varimax rotation. The first factor comprised components related to coping, changes to self and emotional responses. The second factor comprised five of the six identified salient referents (friends, daughter/daughter-in-law, children, medical and allied health personnel, and siblings. The Rotated component loadings are shown in Table 13.

Table 13
Rotated Component Loadings For Two Factors

	Factor	
	1	2
Coping with symptoms	.515	
Not doing what used to do or want to do	.554	
Positive changes to self concept		-.428
Accommodating illness 7 limitations	.626	
Changed self concept	.514	
Reliance on others	.732	
Being frustrated	.725	
Reduced self efficacy	.772	
Being depressed	.490	
Concern about future	.664	
Coping with medical technology	.503	
Friends		.521
Daughter/daughter in law		.413
Children		.608
Medical and allied health personnel		.406
Siblings		.430

CHAPTER 8

DISCUSSION

Increasing concern about chronic illness is expressed from several perspectives. Firstly, there is growing recognition of the financial and social costs of chronic illness (e.g., de Brusk, et al., 1999; McRae & Smith, 1998; Silber, et al., 1999). In Australia, this has become a political issue into which large amounts of effort and health care dollars are directed (Mathers, et al., 2001; Wooldridge, 2000).

The deleterious psychological and social effects of chronic illness have been discussed (Kohler, et al., 1990; Safilios-Rothschild, 1970; Turk & Kerns, 1985). This has led to a biopsychosocial perspective, which considers the interplay of biological, psychological and social aspects of life, which may be affected by chronic illness (Dimond & Jones, 1983; Taylor & Aspinall, 1990).

However, research that adequately develops this approach is rare. There has been broad variation between different disease-specific studies, at all levels of complexity. For example, the lack of consensus in determining the psychological aspects of chronic illness (Fisher, et al., 1982; Johnson, 1980). One of the problems contributing to this lack of consensus may be associated with there being little account taken of the patients' perspectives (Fletcher, et al., 1983; Linn, et al., 1984). While arguing the need for

improved understanding of psychosocial perspectives of chronic illness, Connell (1990) and Cleaver and Pallourios (1994) also noted the paucity of such research. Despite Smith, et al.'s (1991) contention that the effects of psychosocial issues observed in people with rheumatoid arthritis should be applicable to understanding people's experiences of other diseases, no satisfactory comparative work has been undertaken.

Lack of consensus and comparability in the research was also evident in regard to issues of mobility. However, mobility has been related to adjustment and meaning of life (Stenager, et al., 1991; Viemeroose & Krause, 1998), with lower levels of mobility associated with more negative outcomes and expectations.

This study used the symbolic interactionist approach, particularly the theory of stigma (Goffman, 1963) to understand how the use of mobility aids may impact on the measure of attitudes about life post-diagnosis. This theoretical perspective suggests how the relationship between mobility and attitude may be moderated by the use of visible mobility aids, which become potential stigma symbols. The measurement of these attitudes, mobility, and perceptions of support form the basis for both the technical development and testing of the scale, as well as the comparative study of the psychosocial experiences of people diagnosed, and living, with different chronic illnesses.

Scale Development and Validation

The first aim, to assess psychological and social areas of concern and need for people with chronic illness, as represented by the three illness groups, was achieved. The second aim of gauging a measure of physical mobility was also achieved. This was done through the inclusion of Evers (1994) measure of mobility, which was again shown to be reliable with high Cronbach alpha values achieved at all stages of the research.

The third and final aim, to develop a scale to measure psychosocial status of people with chronic illness, resulting in an overall measure of attitude to life, was also achieved. The developed questionnaire was shown to be reliable, as it was associated with high Cronbach alpha scores. It was also shown to satisfactorily discriminate between illness groups.

Support for the construct validity of the developed scale was provided by evidence of the scale's inverse relationship to external locus of control and its positive relationship with internal locus of control.

Furthermore, the specific hypotheses were supported. The first hypothesis, that there will be behavioural and normative beliefs that are found to be consistently salient across all the diagnostic groups, was supported. At each stage of the study, beliefs were found which were salient to all three diagnostic groups.

The second hypothesis, that there will be differences between groups in regard to specific behavioural and normative beliefs was supported. This

is evidenced most clearly by the discriminating variables discerned by each of the functions in the discriminant function analyses.

The third hypothesis, that there will be variation in the overall measure of attitude to life, dependent on the gauged level of mobility was supported. More positive attitude to life was associated with higher levels of mobility.

The fourth and fifth hypotheses were also supported. Driving a car showed the only positive correlation with overall measure of attitude to life. Each of the components of mobility showed negative correlation with overall attitude to life. This relationship became stronger as the use of visible mobility aids became moved from using a walking stick to using a walking frame to using a wheelchair or scooter. The largest negative relationship was found when using a wheelchair or scooter. However, the relationship between overall attitude and being bed bound was found to be less negative than using either a wheelchair or a walking frame. On reflection this possibly provides even stronger support for the hypothesis, as being bed bound may reflect the perception of being less visible, and thereby less likely to face the associated stigma.

The first stage of the research relied solely on participants' responses to inform subsequent scale development. Only issues raised by participants during interviews were included in the scale. The results of subsequent piloting of the scale, in stage two, reflected the accuracy of the scale in

corresponding to the participants' perspectives. This is demonstrated by the extremely high response rate and accuracy of discrimination.

The results of the main study demonstrate that the process provided for items on the scale that still accurately discriminated between diagnostic groups. Within each diagnostic group, variables were identified which were in line with some previous studies and the theoretical areas discussed earlier. The diabetes group reported being less able to do what they wanted to do or used to do, being more reliant on others, and having more social support from siblings, than the arthritis group. This finding of support from siblings is interesting, and suggests a line of investigation about motivation. The diabetes group also reported being more frustrated, and having a greater sense of reduced self-efficacy than the stroke group. The diabetes group reported a negative change in self-concept, but the stroke group did not. It is conceivable that, through the utilisation of this scale, meaningful comparisons between diagnostic groups are possible. It is apparent that this global measure of attitude, adequately identifies variables specific to various diagnostic groups, and is also universally applicable. This research represents an advance in understanding of psychosocial perspectives on chronic illness. This is important in two domains. Firstly, on a technical level, the scale developed is a move toward better understanding in that its development was informed by participants. Furthermore, it is applicable across illness groups. Secondly, the research advances understanding of

psychosocial issues in chronic illness, in the information gained through application of the scale in the final stage. These results represent a more comprehensive understanding of the relationships between issues, including social support. The overall research aims were achieved.

Contribution to Theory

Overall, this study affirms Fishbein and Azjen's Theory of Reasoned Action as a useful perspective and methodological approach from which to gain insight into the psychosocial parameters of chronic illness. It is particularly relevant in ascertaining the perspective of the individual's personal experience and the relevance of that experience. Moreover, it allows identification and clarification of issues in a meaningful and easily accessible way, by implementing the language of people who experience chronic illness, rather than being dominated by the language and terminology of medical and allied health care professionals.

In addition, this study affirms Goffman's (1963) Theory of Stigma as a useful perspective from which to gain insight into psychosocial parameters of chronic illness, particularly issues surrounding changes in mobility and the use of mobility aids. The findings in relation to each of the components of the mobility scale may reflect increments in the degree of stigma the individual perceives from the public, and also the degree of stigma that individual personally equates with the use of the aid.

The work is more reflective of a grounded approach rather than an a priori theory testing model. The interpretations made are speculative in relation to previous research and literature, rather than based upon it. In fact, it is possible that Attitude to Life post Diagnosis is a separate or interactive construct that is separate from self-concept , locus or locus of control etcetera.

Practical Implications/Implications for Practice

From a practical perspective, this study clarifies the complexity of psychosocial correlates of chronic illness, and identifies the varying needs of different groups within the population. It results in a questionnaire, incorporating a scale, which reliably discriminates between diagnostic groups. Moreover, it can be applied at an individual level to aid practitioners in quickly and efficiently identifying a starting point to address the needs of someone with chronic illness. By incorporating subscales pertaining to identified psychosocial issues, mobility and social referents, it provides readily accessible information on several domains, in a single questionnaire.

The Self in Chronic Illness

The results of this research clearly demonstrate the impact chronic illness has on people. The broad range of the measure of attitude to life found in this study (positive and negative) indicates the complex nature, and potential magnitude, of the impact of chronic illness.

What can be seen from the findings is that chronic illness has a differential impact on people. Some people with chronic illness report a positive attitude and some a negative attitude. Some report high levels of perceived social support and some do not. Some are particularly concerned with a particular issue and others are not. The importance and relevance of these, to each person, is shown in particular responses to items on the scales. It is shown through the discriminant results that the differences are different for each specific disease, and that the effects of the diseases can be discriminated by particular items on the scale.

In examining the findings in relation to the theoretical areas discussed in Chapter Two, the contention that the theoretical explanations of behaviour and attitude, which apply to people in general, are applicable, when examining psychosocial adjustment among people with chronic illness, is shown to be true.

Heaven et al., (1991) noted the implications Locus of Control has on behaviour and attitude. The detail of this relationship has been elucidated by several findings showing strongly internal locus of control individuals to also rate themselves as powerful and independent (Hersch & Schube, 1967), and to have positive self-esteem (Epstein & Komorita, 1971). However, neuroticism (Feather, 1967), anxiety (Archer, 1979), and hostility (Heaven, Rajab, & Bester, 1986) have been found in individuals with higher external locus of control. Thus, those people with chronic illness who show an

internal locus of control should feel positive about themselves, and this would be reflected in a positive attitude to life. Conversely, those showing an external locus of control are likely to experience negative emotions such as anxiety and hostility, and this would reflect as a negative attitude to life. The findings of this research, that internal locus of control was positively correlated with attitude and external locus of control was negatively correlated with attitude, support this notion and, thus, adds support to the argument that a sense of control is adaptive (Taylor, 1983, 1989), despite some of the conflicting research of the past (Affleck, et al., 1987; Burish, et al., 1984) which suggested it was more adaptive to give up beliefs in control over chronic illness. Additionally, it must be noted that the process of this research, using participants as informants in the elicitation stage, also provides support for the notion that issues of control are important to people with chronic illness. It was in this first stage, that the saliency of the belief that *I will have less power and control in my life* was identified.

The relevance of the concept of self, in relation to chronic illness is highlighted by the findings of this research. Self-concept refers to the particular package of ideas and attitudes we have about ourselves at any given moment Hamachek (1987). In the first stage of development of this scale, the relevance of issues regarding self-concept, was made clear in the identification of the belief: *there are changes that make me think I'm not the same person I used to be*. It is no surprise that all the identified issues on the

attitude scale can be related to aspects of self. For example, the beliefs *having to rely on other people, having social support, not being able to get around as easily or as much as I want*, may reflect the change in social role and the ability to socialise, and therefore, relate to social self concept. The identified beliefs of *being frustrated, of being depressed, of being concerned about the future*, and of *just having to put up with it*, all relate to the impact of chronic illness on emotional self concept. The beliefs about *having enough knowledge, or whether one is able to work or not*, can be related to intellectual self-concept. Belief about *being aware of limitations*, and *making changes to diet, smoking or drinking habits*, relate to physical aspects of the person's sense of self.

However, the relationship of these issues to self-concept is more complex. While there are some obvious impacts, as discussed above, there are , potentially, multidimensional effects as well. For example, it may be conjectured that, not being able to work, may be a result of physical limitations that prevent the person from being able to travel to the workplace, or to fulfil the physical demands of the job. It may be that the effects of the illness or the treatment and medication regime, are detrimental to the person's intellectual ability, and makes working impossible. The changes in lifestyle and position and sense of self as a result of the diagnosis of, and living with, a chronic illness, may have overwhelmed the person's emotional capabilities, and they are too emotional, or too depressed to work.

Not being able to work, than reduces the person's social contacts and potential for social engagement and so, effects the social self. The change in one component of self-concept may then effect the person's self-concept on another component. For example, if the person's intellectual self-concept is threatened, they may have less confidence to risk themselves in the social area.

Subsequent stages of this research gathered information about individuals' self-concept, and about the four separate components of self-concept: social, emotional, an intellectual and physical. The first and second discriminant functions, both incorporated responses about changed self-concept and reduced self-efficacy, to discriminate between illness groups. More particularly, the contribution of issues regarding social self-concept was incorporated in the issue of being reliant on others, and in identifying issues of social relationships (for example, the importance of the relationship with the daughter or daughter in law, and with brothers and sisters). The results provide evidence of the impact on the emotional self by directly identifying frustration as an issue.

Hamachek (1987) acknowledge the importance of congruency between the ways a person perceives themselves and the way they really are, or would like to be. He noted that various forms of worry, depression, and low self-esteem, are more likely when the gap between these aspects of self broadens. Clearly, issues identified in this research indicate

incongruity between the reality of the way people are with chronic illness, the way they would like to be, and the way they perceive themselves to be. This is highlighted by the identified beliefs of: changes that make me think I'm not the same person I used to be. Further evidence is provided for incongruity, when people acknowledged being depressed, and being concerned about the future. Issues of incongruity may also be understood within Self Discrepancy Theory.

Many of the issues identified in the development of this scale conceivably cause the person with chronic illness to compare themselves unfavourably with others, and, consequently, to feel less positive about themselves (Breakwell, 1986; James, 1890). For example, they could feel *less* able than others when they are not able to do something they want to do or used to do, they may feel that others cope better than they do, or get around better than they do, and so feel less valuable and capable. Not being able to work may make them feel *less* valuable, that they contribute *less*, and that they are *less* important. They feel they have *less* power and control than others, that they are *less* healthy because they have to deal with medications and treatment, that they are *less* competent and *less* independent because they need to be taken care of by doctors and hospitals, and have to rely on others. The possible interpretations a person with chronic illness can apply to all the issues identified in this research are mammoth, but there are clearly many areas related to chronic illness that

provide for the person to see themselves as lacking when they engage in social comparison.

In addition, they may feel that they are aligned with the outgroup, (Goffman, 1963) and are therefore, less valued and esteemed. For example, by making changes to diet, smoking or drinking habits, a person with chronic illness, may feel less like their friends who meet regularly for drinks or dinners. They may withdraw from those social contacts because they felt they no longer fitted in and they felt *less* than the other members of that social group. Such changes can clearly affect the person's attitude to life and potentially make it more negative, as evidenced in this study.

Decreased self-esteem and the inability to feel successful, resulting in a "deep seated sense of deficiency" (Allport, 1937, p. 173), due to an inability to achieve personal aspirations, are reflected in the findings of this research. Many of the issues raised by participants point to being unable to reach personal goals. For example: not being able to do something I used to do or want to do, not being able to get around as much as I used to do or would like to, and not being able to work. This inability to achieve may also be reflected in the identification of frustration and depression. The importance of these issues is highlighted by their inclusion in the discrimination between illness groups. The most powerful predictor variable for discriminating between arthritis and diabetes groups was: *not doing what I want to do or used to do*. The two most powerful predictor variables for

discriminating between stroke and diabetes groups were being frustrated, and reduced self-efficacy. These variables strongly demonstrate the importance of issues around achieving personal aspirations, for people with chronic illness.

Reflected appraisals affect a person's feelings about themselves (Banaji & Prentice, 1994; Gergen, 1972; Schlenker, 1980), and a person who projects positive self-esteem (e.g., confidence in personal ability) is more likely to elicit positive feedback (Hamacheck, 1987). In examining the findings of this research it is necessary to consider that a person with chronic illness, whose actual abilities may have diminished, whose self-evaluation is less than optimal, and who may show obvious signs of their illness (such as tremor, speech impediment, or using a walking aid), may perceive negative reflected appraisal. This can be related to their reflecting negative self-esteem. Since self-esteem and reflected feedback are mutually reinforcing, this may have a great impact on their feelings of self-worth and self-esteem. The findings support this. Less positive attitude was associated with the use of mobility aids. This may be consistent with perceived negative feedback from others in response to the mobility aids, and so the perceived reflected appraisal for the person with chronic illness is negative. In addition, by being unable to work, or by being unable to get around and do things like they used to do, people with chronic illness have a reduced opportunity for receiving positive feedback from others.

Exacerbating this problem is the likelihood that the person with chronic illness will be projecting negative self-esteem. This is demonstrated in the findings in items pertaining to being frustrated and depressed. It may also be reflected in the emotions people feel in regard to many of the other issues identified. For example, someone who is frustrated and depressed, and may feel less valuable for many of the reasons mentioned earlier (such as not working or being reliant on others), will probably project negative self-esteem. Their sense of self and self-worth is diminished, they project negative self esteem, and thus, perceive negative feedback from others. This is consistent with the current findings. If sense of self is diminished the person, reflecting negative self-esteem, is likely to have a negative attitude to life.

Marsh's (1989) development of understanding the stability of self-concept by adolescence and early adulthood, may explain the identification, in this research, of a preponderance of issues directly relating to or affecting the person's sense of self. If the sense of self is developed and relatively stable by adulthood, then any threats to that sense of self are understandably of great consequence. They would, therefore, be the focus of attention of the person with chronic illness, as demonstrated in the findings.

One of the facets of self-concept that Marsh (1986) could relate to differences in self-esteem was the physical facet. This research supports the idea that the physical component of self esteem is important. The physical

aspects of self related to mobility and to the use of mobility aids, clearly impacted on attitude to life. Several of the predictor variables identified in the discriminant function analysis may also relate to physical issues. For example, not being able to do what I used to do or want to do, may be due to physical disability and being unable to do such things as, walk, or dress, or drive a car. Being reliant on others may also be due to physical constraints, relying on others for assistance with personal hygiene, transport, home maintenance etc. The important discriminating variables identified: being frustrated, reduced self-efficacy, changed self-concept and not doing what I want, may all be related to possible changes in physical ability and physical self-concept. As discussed earlier, the relationship between physical self-concept and the potential for changes to reflected appraisal, which are detrimental, may explain the importance of this facet of self-concept in explaining changes in self-esteem.

The findings of the current research are consistent with the work of Marsh (1987). That study found a clear hierarchy related to esteem and the physical, social, and emotional components of self-concept. In chronic illness, the changes in the physical self-concept may result from changes in physical abilities, strength, or possibly, appearance. As these changes in physical ability, potentially limit social opportunities and change the individual's social roles, there may be changes to the individual's emotional responses to such change and to life in general. The current research

findings that the impact of chronic illness on all of these facets of self concept may explain changes in self-esteem and is reflected in the measure of attitude to life.

The focus of Self Discrepancy Theory (Higgins, Bond, Klein & Stauman, 1986), in the context of people with chronic illness is supported by the findings. There were many interpretations wherein the individual with a chronic illness perceived discrepancy between how they actually are and how they wish to be, or how they or others, think they ought to be. This was evident in many of the issues identified in the first stage of the research. For example, changes that make me think I'm not the person I used to be. Several issues identified, while not directly voicing the desire to be a particular way, suggest that, in fact, the person wishes they were something other than what they actually are. For example, by identifying concern about being able to work, of having to rely on others, of being less powerful and having less control, people with chronic illness are reflecting a wish that they were able to work, did not have to rely on others, and had more power and control in their life.

The normative referent scale comprised people who were considered important and whose opinion mattered. The strong reliability values for this scale demonstrate the potential for people with chronic illness, who perceive change to their sense of self, to be affected by how others think they ought to be. In this study, the findings suggest that people with chronic illness are

most likely to be influenced by their partner (spouse), friends, daughters, children, medical practitioners and siblings. In discriminating between illness groups the important others identified were daughter/daughter-in-law, medical personnel, and siblings. The most powerful discriminating variable in this regard was siblings. These findings may be partly understood through Self Discrepancy Theory.

The question remains though, whether the identified social referents reflect a group which enhances the person's sense of self and attitude, and other unidentified others are more likely to participate in the generation of self-discrepancy between the persons actual abilities and how others think they ought to be; or whether the identified group of social supports represent the most significant people in the life of someone with chronic illness and it is, therefore, this group who are more able to contribute to possible discrepancy between the actual and ought self.

The findings of this thesis demonstrate how chronic illness threatens the individual's self-identity. These threats challenge either the content or the value dimensions of identity (Breakwell, 1986). On the content dimension, threats "challenge the continuity or distinctiveness of self-definition. They query whether you can continue to be what you think you are" (p. 48). In regard to the value dimension "threats challenge self-esteem. They query whether what you are is any good" (p. 48).

The issues raised by participants, and subsequently included on the

scale, predominantly related to self-concept, and indicated that people with chronic illness struggled with not being what they thought they were, and so their self-concept was threatened on the content dimension. For example, they noted not being able to do something they used to do, not being able to get around as much as they wanted, not being able to work, not being the same person they thought they were, having less power and control, being depressed, relying on others. Presumably, most adults strive to live their lives in ways that are most comfortable psychologically, and to engage in behaviours that they value. The issues, above, suggest a problem for people with chronic illness in recognising the changes to themselves and their lives.

Through various processes, such as social comparison, and reflected appraisal, the person with chronic illness is then forced to evaluate the changes associated with their illness. They are forced to question whether what they are now is valuable. Again, understanding that most adults can be expected to strive to live in a way that they value, it is likely that being forced to change (due to a chronic illness) threatens their sense of self on the value dimension. For example, if they had valued not working, relying on others, and not taking control in their life, then, presumably, they would have already developed a lifestyle based on those ideas.

Stigma, Mobility and Attitude

These findings support Goffmans (1963) theory of stigma in relation to people with chronic illness. Clearly, the results with respect to the effect

on attitude of the use of visible mobility aids, is negative. There was a negative attitude to life associated with using a walking stick, a wheelchair or scooter, and a walking frame. Interestingly, Goffman suggested that that stigma depends on the context and the perceiver. There is support for this idea in the findings, indicating that it was not simply increasing restriction of mobility that impacted on attitude of people with chronic illness. When mobility was at its worst and people were bedbound, the measure of attitude became more positive than when they used one of the visible mobility aids.

It is likely that people using the aids, are still out in public, to varying degrees, and would thus, be recipients of negative appraisal and would perceive stigma. This problem is alleviated when the person is restricted to bed and is less likely to interact with the public.

The results indicate other ways in which the person with chronic illness may have faced more potential stigma, such as being unemployed (I won't be able to work). The deficits associated with chronic illness, as discussed earlier, result in the person with chronic illness being unable to fulfil social roles that they used to do or that others deem they should do. This opens them to further stigmatisation, through, negative reflected appraisal, negative social comparison, and discrepancy in self-concept, isolation from social groups resulting in exclusion from social ingroups or alignment with an outgroup.

In addition to findings relating attitude to mobility, through stigma, this research may reflect a more general concern about mobility in chronic illness. For example, apart from the mobility scale per se, issues were identified that relate to getting around as much as I would like, and relying on others. This provides some support for considering that mobility related issues as one of the most stressful aspects of chronic illness (Beulow, 1991).

The identified issues around self-concept may also reflect a mobility related dimension and contribute to the negative change in attitude associated with the overall measure of mobility. This is in line with research suggesting mobility/disability negatively affects self-esteem (Elliot, McNair, Herrick, Yoder, & Byrne, 1991; Walsh & Walsh, 1987, 1989), and that functional loss is significant in the emotional impact of chronic illness (Devins & Seland, 1987). Again, mobility may contribute to the current findings of depression and frustration.

The findings provide support and evidence for understanding chronic illness through theories that address concepts of self. Self is the issue, rather than chronic illness. The important lesson to note is that people with chronic illness are *people*, they are not a manifestation of an illness, and they cannot be completely understood by that illness. However, the research does indicate that there are some issues that are specific to illness groups and that understanding these, in context of the person's life, provide an insight to their needs.

Practical Meaning of Results

The results of cronbach's alpha show that the scales developed to measure attitude to life, perceived social support and, a measure of overall mobility are reliable. This was demonstrated in both the pilot study and the main study. The combination of the attitude and the perceived social support scales, as representing issues important to people with chronic illness, also show good reliability.

In the final stage of the research, a measure of locus of control (Wallston, et. al, 1978) was included in order to ascertain discriminant validity of the attitude to life scale. The results indicate that the measure of positivity and negativity of attitude, is consistent with the expectations in relation to locus of control. Thus, the scale has demonstrated discriminant validity for the construct.

The results of the discriminant function analysis resulted in high levels of discrimination between the illness groups. This is demonstrated by the scales capability to correctly classify 79.4% of cases. In the process of discriminating, the scale highlights relevant issues and concerns for each illness group. This enables the development of services that are more closely aligned to the needs of the patient group.

On an individual basis, the scale potentially recognises an overall measure of the level of attitude to life, or perceived social support, which could suggest to health practitioners that the individual is susceptible to

psychosocial problems that may have a detrimental impact on disease, treatment, and life outcomes. Closer examination of the content of an individual's scores for particular items would tag specific areas of need.

The findings of this study suggest that there is some element of stoicism in some people with chronic illness. This suggested by the identification of being able to *put up with chronic illness, or make the best of it*. While this may be a way that some people are able to maintain a sense of control or power to some degree, it is also problematic in that people may not be talking about issues of concern to them. By administering and analysing the scale, and identifying individual's issues, health care providers could facilitate the discussion of these issues. In trying to remain stoic in the face of chronic illness, some people may actually not be able to express their feelings, or may dismiss them as irrelevant. By completing the scale, people with chronic illness are provided with a discourse through which they can begin to frame their experience and express their concerns.

The versatility of this scale in being able to discriminate between illness groups, while still having high salience across the various illness groups, addresses the problems of previously developed scales. These were often too specific, in addressing only particular aspects of a person's experience (e.g., Finger, 1993), and thus, not providing a complete understanding of the breadth of psychosocial issues in chronic illness. Some scales were too specific in being only applicable to one illness (e.g., Cleaver

& Pallourios, 1994), and, therefore, precluding comparisons across illness groups. Other scales were too general in approach to provide clarification of the detail of important psychosocial issues (e.g., Koivisto, et al., 1993, Skyler, 1991), and therefore, did not provide a basis for clinical application.

Importantly, this scale can be utilised cost effectively. There are negligible costs in reproducing and interpreting the questionnaire, and most people with chronic illness can complete it without assistance from health care providers. It is conceivable that a person with a chronic illness could complete the questionnaire while sitting in a waiting room, or at a convenient time outside the health care setting. It could then be handed to the healthcare provider or mailed back to the healthcare provider. The instrument can be administered, scored and basically interpreted by minimally qualified personnel. It provides for the identification of relevant psychosocial needs and concerns, without the delay or cost involved in referral to psychologists or psychiatrists. However, it also provides for the identification of levels of attitude or perceived social support that may warrant such referral, thus making the process of referral more relevant. This results in better utilisation of health care dollars, either by government or by individuals. This is highly relevant in light of increasing demands on the healthcare system (Mathers et al., 2001), and growing costs related to chronic illness (De Busk et al., 1999).

CHAPTER 9

CONCLUSION

Introduction

Chapter Eight emphasised the importance of understanding chronic illness. Particularly in light of increasing demand in an aging population, and the costs to healthcare. The chapter then elaborated the connection between the findings of this research and various theoretical perspectives, giving examples from the data, which clarify the theoretical understanding of the impact of chronic illness. This was related primarily to theories regarding sense of self, and then to the understanding of the impact of mobility issues.

In essence, chapter eight clarified what we learned from the research in regard to psychosocial issues of chronic illness. Finally the chapter explained what the development of the scale means in terms of improved ability to investigate the psychosocial issues of chronic illness.

This chapter provides conclusions about the significance of the research and discusses the limitations of the present study. It then discusses suggestions for future research.

Advances Arising from the Study

This research set out to develop a scale which could be used to identify areas of need and concern for people with chronic illness, and which would also discriminate between diagnostic groups, thereby allowing comparison. It is important that the scale have discriminatory power, in order to accommodate the potential differences experienced by people in different diagnostic categories. As discussed earlier, an overall measure of attitude was determined, as representing a measure of adjustment. A measure of perceived social support was also determined.

In successfully developing such a scale, the results of this research provide a means to measure psychosocial status of people with chronic illness, and provide a way for busy medical centres to identify a starting point in appropriately meeting patients' individual needs.

Moreover, the scale allows identification of differences and similarities in areas of concern and need, across diagnostic groups. Potentially, this enables efficient development of services to meet the unique needs of patients with particular diagnoses while simultaneously allowing for appropriate joint utilisation of services across diagnostic groups.

Previous research was unable to clearly identify the overall psychosocial impacts of chronic illness, the psychosocial consequences of chronic illness, and the psychosocial needs of people with chronic illness.

Identification of the issues which impede adjustment and coping is paramount to the psychosocial well-being of the patient, families, and to the course of the disease as it is effected by disease management.

However, this within the difficult constraints of the hospital system in particular, and the medical system at large. Access to a psychologically trained professional, which would allow patients to explore and identify their psychosocial needs, is largely impossible due to staff shortages and limited funding. Thus, this reliable and valid instrument which can be administered relatively easily and quickly, or which can be self-administered, is potentially invaluable to patients struggling to verbalise their experiences and to practitioners trying to optimise treatment outcomes.

Limitations of the Study

In the final stage of the research, the response rate was considerably lower than it had been earlier. Four hundred questionnaires were mailed, and total returns were only 56.25%. Considering this was a clinical population and a mailed survey, however, this is quite reasonable. Some issues arose because of hospital records. Twenty-five were returned marked wrong address, and eight had been either misdiagnosed or not made aware of their diagnosis. One replied, but noted multiple complicated diagnoses which were not recorded in their hospital record. Two were deceased, and relatives notified the researcher. Four who were unable to complete the questionnaire, advised that they were constrained by health related issues.

The study was limited in that it only represents the attitude of individuals with chronic illness at a given point in time. However, that is also a benefit of the study, because it allows for comparisons to be made over time.

It is also limited in that only three chronic illness groups were represented. The study attempted to access a broad cross section of participants from the illness groups, including a range of ages and both men and women. It is possible that there are lifestage and gender effects that have not been elucidated in this study.

It would have been ideal to factor analyse the data within groups, but it was not possible due to the numbers of participants available. In this case, factor analysis would breach the underlying assumptions of the analysis too severely.

Future Research

Future research could measure perceived stigma and include Specific analyses relating to the types of mobility aid used. Further clarification and analysis of the differences on these measures over each disease group may also be useful. Further research may also utilise a ‘healthy’ control group in order to highlight the impacts of chronic illness on the identified domains.

The application of the developed questionnaire as a measure to gauge changes in attitude over time, particularly to measure potential changes associated with treatment or therapeutic programs, would be extremely informative. Similar longitudinal application in relation to changes in mobility would also be informative, and may guide patients and therapists in considering the use of mobility aids, or in improving attitude toward mobility aids.

It is encouraging to note that so many individuals made the effort to explain their non-participation, and many offered encouragement with their apologies. Many respondents also included additional letters with their completed questionnaires, offering support, thanks and encouragement. Such unsolicited correspondence may indicate that the scales were truly meaningful to many participants, and that the language used in the scales was accessible and relevant. Similar responses from participants and medical practitioners during the elicitation interview stage, highlight the need felt by patients and doctors to address psychosocial issues, and facilitate discussion of these issues.

Future research could benefit from extending the application of the instrument to other chronic illnesses or conditions. As well as these cross-diagnostic studies, cross-cultural studies of the issues discussed in the present study could also be enlightening.

If the instrument can be validated for use with multiple groups, it can potentially become a standard tool in aiding practitioners who deal with the growing and overwhelming issue of chronic illness, enabling faster response to the needs of those with chronic illness. It could also efficiently provide information regarding treatment program outcomes.

The next most useful step in regard to this scale would be trial testing in situ, to ascertain acceptance by people with chronic illness, ease of utilisation, and therapeutic outcomes based on identified needs.

Using the scale to discriminate between clinical and non-clinical samples, in a similar fashion to discriminating between illness groups, would be informative. This would provide for a clearer examination of the effects of chronic illness on attitude to life and perceived social support.

At the time of writing, the author had successfully and meaningfully utilised the scale in providing treatment for people with chronic illness, and guidance for medical practitioner colleagues in dealing with chronic illness in the clinic setting. The scale had also been utilised in relation to people with chronic injury through workplace accident and motor vehicle accident. As a result of this successful utilisation of the scale, to inform therapeutic practice, negotiations are currently underway with a view to forming a rehabilitation service, in joint co-operation with medical practitioners.

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APPENDIX A

HOSPITAL APPROVAL LETTERS

Our Ref: 121/95

December 22, 1995

Ms Kaylene Evers
Department of Psychology
PO Box 14428
M.M.C. Melbourne 3000

Dear Ms Evers

RE: Project No 121/95 An investigation and comparison of the psychosocial effects of chronic illness across three illness groups. The role of educational and psychological intervention

I am pleased to inform you that your research project has been approved as per your application and subsequent amendments on the understanding that you observe the National Health and Medical Research Council Statement on Human Experimentation (see over).

The Committee requests that:

- 1) it is provided with a copy of the questionnaire when it becomes available;
- 2) you seek permission from the senior nurses and clinicians to recruit patients from their departments;
- 3) clinicians screen records for psychiatric illness before the patients are approached;
- 4) you ensure that no identifying material is taken off the premises;
- 5) you take into account the bias that may occur through the selection method.

The Committee expressed strong reservations about the comparability of the three patients groups, particularly the stroke group. Therefore, it is suggested that you have more detailed discussion with Dr Frayne about the nature of patients in the Stroke Unit before commencement.

It is now your responsibility to ensure that all people associated with this particular research project are made aware of what has actually been approved. Any change to the application which is likely to have a significant impact on the ethical considerations of this project will require completion of a "Request for Amendment" form (available from General Administration) to be forwarded to the Committee for consideration.

In addition, although ethical approval has been granted, should any aspect of this research project impact upon Hospital Services, in particular nursing resources, this must be discussed with and agreed to by the relevant head(s) of department prior to commencement of the project.

Upon completion of the project please provide the Ethics Review Committee with a synopsis of your findings. In those instances where the project is to continue for more than eighteen months, a synopsis of progress made during the preceding year must be forwarded to the Secretary of the Ethics Review Committee during the month of August.

Yours sincerely



Rowan Frew
Administrative Officer
Ethics & Research

cc: Manager, Nursing Resources, Alfred Hospital



POSTAL ADDRESS
PO Box 315 Prahran
Victoria 3181 Australia

ALFRED HOSPITAL
Prahran Victoria Australia
GENERAL MEDICAL CENTRE
Caulfield Victoria Australia



Ivanhoe Manor Private Rehabilitation Hospital

ref/don-0304

23rd January, 1996

Ms Kaylene Evers
Victoria University
P.O. Box 14428
M.M.C.
MELBOURNE VIC 3000

Dear Ms Evers,

Re: Investigation and comparison of the Psychosocial Effects of Chronic Illness across three illness groups. The role of education and psychological intervention.

Your request to conduct the above project at Olympia Private Rehabilitation Hospital has been considered by the Ethics Committee and been approved. Your contact person will be Mrs Rosalie Maher, Director of Nursing.

Some concern was raised regarding the availability of hospital facilities, you will need to discuss this with Ms Maher to ascertain that they are adequate to enable you to proceed.

Given the time span of the project, the committee requests an annual report be submitted to them during the research. Based on that report, the committee maintains the right to withdraw approval.

I wish you every success in your undertaking and look forward to your annual reports.

Yours sincerely,

[Signature]

Pam Gunther
Secretary
Ethics Committee
Ivanhoe Manor & Olympia Group of Private Rehabilitation Hospitals

PETER F J RYAN
M.B.B.S.(Hons),F.R.A.C.P.,F.A.F.R.M.
CENTRE FOR RHEUMATIC DISEASES
WESTERN RHEUMATOLOGY CENTRE

SUITE 34 PRIVATE CONSULTING ROOMS
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PROVIDER NO: 237412 J

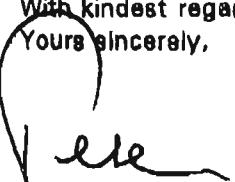
8 November 1995

Ms. Kaylene Evers,
Victoria University of Technology,
P.O. Box 14428,
M.M.C.
MELBOURNE 3000.

Dear Kaylene,

I do apologise for not writing to you formerly. As I intimated to you per phone, I would be delighted to be an associate involved in your research project titled, "An investigation and comparison of the psychosocial effects of chronic illness across three illness groups: The role of educational and psychological intervention". Please let me know if there is anything else I need to do. I also can be contacted via Email at Peter @ Alfred. Med.Monash.edu.au.

With kindest regards,
Yours sincerely,



PETER RYAN



**The Alfred
Healthcare Group**

**Ewen Downie Metabolic Unit
Alfred Hospital
Commercial Road
PRAHRAN VIC 3181**

Tel: 9276 2460
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28 August 1995

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Facsimile (03) 276 6434

**Ms. Kaylene Evers
Department of Psychology
Victoria University of Technology
FAX: 365 2218**

Dear Ms. Evers,

re: Research project on psychosocial effects of chronic illness

In principle I see no difficulty in assisting you with this project, provided hospital Ethics Committee approval has been gained.

To translate that in principle agreement into practice, I would wish to better understand the nature of the questionnaire and the proposed information/education interventional strategy, and to meet you to discuss it. I am away from 6-18 September so perhaps we could discuss this further on my return.

You may certainly cite this letter as in principle agreement for your submission by 1 September 1995.

With kind regards,

Yours sincerely,

Duncan J. Topliss MD FRACP
Deputy Director
Department of Endocrinology and Diabetes/
Ewen Downie Metabolic Unit
Associate Professor of Medicine

Dr Judith Frayne

NEUROLOGIST

Provider No: 199733B

Suite 25, First Floor
CABRINI MEDICAL CENTRE
Isabella Street
Malvern 3144
Telephone: 9509 9411
Facsimile: 9576 0334

17 September 1998

Ms Kayleen Evers
Victoria University

Fax No: 9365 2218

Dear Ms Evers

RE: **PROJECT - PSYCHOSOCIAL ASPECTS OF CHRONIC
ILLNESS**

I am pleased that you are able to commence your project. I would be happy for you to contact patients that you identify as suitable for this project.

With kind regards



JUDITH FRAYNE

APPENDIX B

ELICITATION STAGE RESPONSE SHEET

AGE..... GENDER..... DISEASE/CONDITION.....

Elicitation of salient beliefs:

1. What do you see as the advantages associated with your illness today?

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.....
.....
.....

2. What do you see as the disadvantages associated with your illness today?

.....
.....
.....
.....

3. Is there anything else you associate with your illness today?

.....
.....
.....
.....

4. Are there any groups or people who are important to you, who are advantaged by your illness as it is today?

.....
.....
.....
.....

5. Are there any groups or people who are important to you, who are disadvantaged by your illness as it is today?

.....
.....
.....
.....

6. Are there any other groups or people who come to mind when you think about your illness today?

.....
.....
.....
.....

THANKYOU AGAIN FOR YOUR HELP

APPENDIX C

STAGE 1 CONSENT AND INFORMATION SHEETS

THE ALFRED HEALTHCARE GROUP

Project title: An investigation and comparison of the psychosocial effects of chronic illness across three illness groups: The role of educational and psychological intervention.

Name(s) of researcher(s): Dr. Wally Karnilowicz
Kaylene J. Evers
Dr Duncan Topliss

EXPLANATORY STATEMENT: Stage 1

You are invited to participate in this research project which aims to discover how people feel about coping with a chronic condition or illness on a daily basis. In particular, we hope to find out how these conditions may effect emotional and social well-being, and interactions with other people.

This stage of the research will gather information about any matters or people or groups of people (including organisations) that seem relevant to you in relation to your illness or your life subsequent to diagnosis. To be eligible you should be over 18 years of age and not have a concurrent diagnosis or medication regime which would influence results. Confirmation of these details will be made through medical records, with your approval. The information you supply will be anonymous, and no individual will be identified. The records will be kept in coded form for seven years following the completion of the research, after which time they will be destroyed.

You are free to withdraw from the project at any time without prejudice to your continuing treatment. Participation will take approximately 20 minutes of your time and will occur at a time and place convenient to you.

If you would like information about the outcomes of the study please advise either Wally Karnilowicz or Kaylene Evers.

The information from this stage will be used to develop a questionnaire for more wide spread investigation. The ultimate aim is to develop a means of determining the needs of persons with chronic illness, and to develop a program of information and education which will then meet these identified needs.

The research is conducted under the auspices of the hospital and Victoria University, Department of Psychology. The project is being conducted by Kaylene J. Evers, and is under the academic supervision of Dr. Wally Karnilowicz, and the professional supervision of Professor Susan Moore.

If you wish to discuss any matters concerning the project please speak to Kaylene Evers on 9365 2751 or contact Dr. Wally Karnilowicz on 9216 8106. To discuss the project with a hospital representative please contact Dr Duncan Topliss on 9276 2460

THANK YOU FOR YOUR PARTICIPATION

Chief researcher's signature:

Phone no(s):
9216 8106

THE ALFRED HEALTHCARE GROUP
Commercial Road, Prahran Victoria 3181

SUBJECT IDENTIFICATION
U.R. No.

NAME
ADDRESS.....
.....

DATE OF BIRTH.....

CONSENT FORM FOR RESEARCH PROJECT FOR COMPETENT SUBJECTS

PROJECT No. TITLE ..An investigation and comparison of the psychosocial effects of chronic illness across three illness groups: The role of educational and psychological intervention.....

CHIEF RESEARCHER ..Dr Wally Karnilowicz.....

1. I, the undersigned hereby consent to my involvement in the above research project.
2. I acknowledge that the nature, purpose and contemplated effects of the project so far as it affects me have been fully explained to my satisfaction by the researcher and my consent is given voluntarily.
3. I have received the Explanatory Statement and am familiar with the nature of the study including the anticipated length of time the study will take, the frequency with which visits and tests will be performed, and an indication of any discomfort which may be expected.
4. Although I understand that the purpose of this research project is to improve the quality of medical care, it has also been explained that my involvement may not be of any benefit to me.
5. I have been given the opportunity to have a member of my family or a friend present while the project was explained to me.
6. I have been informed that no information regarding my medical history will be divulged to unauthorised persons and that the results of any tests involving me will not be published in such a way as to reveal my identity.
7. I understand that my involvement in the project will not affect my relationship with my medical advisers in their management of my health. I also understand that I am free to withdraw from the project at any stage.
8. I confirm that it has been explained to me that the hospital has an Ethics Committee which:
 - (a) has approved the above project
 - (b) ensures that explanations such as I have received conform to ethical standards which this Hospital is required to observe, and
 - (c) has officers who may be authorised to contact me to check whether the proper standards are being observed and who are pledged to preserve the confidentiality of my involvement.

Signed this day/...../.....

Witness Name.....Signature..... this day/...../.....
Address.....

Researcher Name.....Signature.....

**IVANHOE MANOR AND OLYMPIA GROUP OF HOSPITALS
at OLYMPIA PRIVATE REHABILITATION HOSPITAL**

EXPLANATORY STATEMENT (Stage 1):

**AN INVESTIGATION AND COMPARISON OF THE
PSYCHOSOCIAL EFFECTS OF CHRONIC ILLNESS.**

This research is interested in how people feel about coping with a chronic condition or illness on a daily basis. In particular, how it may effect emotional and social well-being, and interactions with other people.

This stage of the research will gather information about any matters or people or groups of people (including organizations) that seem relevant to you in relation to your illness or your life subsequent to diagnosis. To participate you must be over 18 years of age and not have a concurrent diagnosis or medication regime which would influence results. Confirmation of these details will be made through medical records, with your approval. The information you supply will be anonymous , and no individual will be identified.

You are free to withdraw from the project at any time without prejudice. Participation will take approximately 20 minutes and will occur at a time and place convenient to you.

If you would like information about the outcomes of the study please advise the researcher.

The information from this stage will be used to develop a questionnaire for more wide spread investigation. The ultimate aim is to develop a means of determining the needs of persons with chronic illness, and to develop a package of information and education addressing these needs.

The research is conducted under the auspices of Olympia Private Rehabilitation Hospital and the Victoria University, Department of Psychology. The project is under the academic supervision of Dr. Wally Karnilowicz.

If you wish to discuss any matters concerning the project please speak to Kaylene Evers on 9365 2336 or contact Dr. Wally Karnilowicz on 9216 8106.

THANKYOU FOR YOUR PARTICIPATION.

CONSENT FORM

TITLE OF PROJECT: An investigation and comparison of the psychosocial effects of chronic illness across three illness groups: the role of educational and psychological intervention.

1. INVESTIGATOR

I, Kaylene J. Evers have fully explained the aims, risks and procedures of the research project to.....

2. PARTICIPANT

I,.....(print name)

of.....(address)

agree to take part in the research project described in the attached explanation, being conducted by Kaylene J. Evers who has fully explained the research to me and given me a copy of the explanatory statement.

I understand that I am free to withdraw from the project at any time and I have the opportunity to have a friend or family member present while the project is explained to me.

Signed.....Date.....

I.....witness that the above consent has been given freely after due explanation of procedures.

Signed.....Date.....

APPENDIX D

SALIENT BELIEFS AND NORMATIVE REFERENTS OVERALL REPRESENTING *CHRONIC ILLNESS*

Salient Beliefs elicited over entire sample (three diseases) f

Symptoms	47
Can't do something like I used to do or want to do	35
Mobility, getting around	27
Stoicism	20
Knowledge of illness or disease	19
Positive changes to me	15
Accommodate illness, know limitations	14
Self concept	14
Work	13
Have to rely on others	13
Frustration	12
Decreased power/control	12
Hospitals/doctors	12
Depressed	11
Changes to diet, smoking, drinking habits	11
Concern about the future	10
Social support	10
Medical regime, technology	9 ***75% cut
No advantages	8
Isolated/lonely	8
Increased emotionality	8
Anger	8
Worry about health	7
Worry about dying	7
Finances	6
Changed social life	6
It was a shock, hard to accept	6
Communicating with significant others	5
More time at home	4
Moved house	3
Home help	3
Boredom	3
Difficult diagnosis, disbelief by others	3
Guilty over effect on others2	2
Various beliefs with frequency of 1	12
TOTAL	403

75% = 302.25 = 18 salient beliefs

**NORMATIVE REFERENTS ELICITED OVER ENTIRE SAMPLE
(THREE DISEASES)**

Spouse	16	
Friends	12	
Daughter (daughter in law)	11	
Children	7	
Medico's physio's etc.	7	
Brother/sister	5	***75% cut
Aunt/uncle/cousin/niece/nephew	5	
Son	4	
Parents, mother, father	3	
Grandkids, grand nieces	3	
Social clubs, organizations	3	
Me or self	2	
Family	2	
Various referents with frequency of 1	5	
TOTAL	95	

75% = 71.25 = 6 normative referents

APPENDIX E

SALIENT BELIEFS AND NORMATIVE REFERENTS FOR EACH ILLNESS GROUP

SALIENT BELIEFS ELICITED FROM PERSONS WITH RA

NO ADVANTAGES	4
LIMITED LIFESTYLE	1
CANT REMEMBER	1
HAVE TO PLAN ACTIVITY TO ACCOMMODATE RA	1
CALMED ME DOWN	1
SLOWED ME DOWN	1
SPEND MORE TIME AT HOME	1
CHANGED MY LIFE	1
DON'T MIX MUCH SOCIALLY	1
MISSING OUT ON PARTICIPATING WITH KIDS	1
DON'T HOLIDAY AS SHOULD	1
GUILT OVER EFFECTS ON FAMILY	1
BIT SLOW NOW	1
NEVER LET IT STOP YOU WORK	1
LOTS OF CHALLENGES	1
RELIED HEAVILY ON WIFE	1
ADAPTED FARM MACHINERY	1
ALLERGY TO MEDICATION	1
DISAPPOINTED 'COS INACTIVE	1
ANNOYED AT CHILDREN MAKING DECISIONS FOR ME, GETTING BOSSED AROUND	2
WEIGHT GAIN	2
HAVE TO BUY SPECIAL SHOES	1
HOME HELP IS USELESS	1
A LONER AND LOVING IT	1
BECOME A FATALIST	1
CAN'T DRIVE, STILL DRIVE	2
WIFE HAS TO DO WORK THAT'S NOT A WOMAN'S JOB	1
I'M ANSWERABLE TO WIFE NOW	1
EMASCULATED	1
DISEMPowered	1
LOST EYESIGHT	1
GET TIRED	3
CAN'T WALK SO MUCH AS USED TO	3
HUSBAND HAS TO CUT UP FOOD	1
TROUBLE GETTING AROUND	1
WISH I COULD DIE THE PAINS SO BAD SOMETIMES	1
DON'T GO ANYWHERE NOW	1
HAPPY BEING HOME	1
AWKWARD TO LEARN TO USE EQUIPMENT	1
READ ABOUT IT A LOT	1
HAVE TO LEARN TO LIVE WITH IT	1
NEVER LET IT BOTHER ME, STOIC	1
HAPPY TO DO WHAT NEEDS TO BE DONE	1
POSITIVE OUTLOOK	1
CAN'T DO WHAT I USED TO DO	2
CAN'T DO THINGS I'D LIKE TO DO	3
CAN'T BE AMONGST PEOPLE AS MUCH	1
I NOW THINK BEFORE I ACT	1
MORE TIME WITH KIDS/FAMILY	1
DEVELOPED HABIT OF THINKING & WORKING THINGS OUT	1
WORK SMARTER	1
DIFFERENT LIFESTYLE	1

ANGRY WITH MEDICOS	1
CAN'T WORK	2
FRUSTRATED	1
TOLD IT WAS IN MY MIND BEFORE BEING DIAGNOSED	1
FRIGHTENED BY PROSPECT OF FUTURE TREATMENTS	1
CAN'T TOILET PROPERLY	1
PERSONAL MANAGEMENT ISSUES	1
PUTTING UP WITH SYMPTOMS	1
POWER IMBALANCE IN DR/PATIENT RELATIONSHIP	1
DEPERSONALIZED BY HOSPITAL SYSTEM	1
MALTREATED BY DOCTORS	1
RESENT BEING TRATED LIKE IDIOT	1
NOT ENOUGH INFO	3
GAVE UP BOWLS (SPORT)	1
LOSS OF PERSONAL STRENGTH	1
KEPT IN DARK BY MEDICOS	1
DISBELIEF BY COMMUNITY AT LARGE	1
CAN'T DO WHAT I'D LIKE TO DO	1
CAN'T DO THINGS AS WELL AS BEFORE	1
CAN'T CLEAN WINDOWS/oven	1
BOREDOM	1
I'VE BECOME A BIT MORE OF A LONER	1
DON'T HAVE THE DRIVE TO MEET THE DEMANDS OF SOCIALIZING	1
LIVE FOR TODAY	1
HAND GETS TIRED	1
QUITENEDME DOWN	1
FIND OUT WHO YOUR FRIENDS ARE	2
RESTRICTED MOVEMENT	1
RESTRICTED LIFESTYLE	1
RESTRICT GOLF AND SPORTING ACTIVITIES	1
CAN'T COMPETE AS I'D LIKE	1
MOVED TO AUSTRALIA	1
DO HOUSEWORK	1
USE WHEELCHAIR	1
HAVE TO KEEP MOVING, CAN'T SIT STILL	1
IF I SIT STILL I THINK ABOUT EVERYTHING AND THEN FEEL SICK	1
LOST SOME FRIENDS	2
RESIGNED TO BLEAK FUTURE	1
UPSET	1
LOTS OF DISADVANTAGES	1
TRouble DOING EVERYDAY TASKS	2
NEED COUNCIL HELP	1
SOME DAYS CAN'T DO ANYTHING	1
FEEL TERRIBLE	1
NO SEX LIFE	1
ACCEPT LIMITATIONS	1
DISCOMFORT	1
FRUSTRATED	2
FRUSTRATED AT LOSS OF INDEPENDENCE	3
ANGRY	3
RESENTMENT TOWARDS FAMILY	1
CAN'T MANAGE PERSONAL HYGIENE (HAD TO CUT HAIR)	1
WANT TO MAINTAIN INDEPENDENCE, LOST INDEPENDENCE	3
UNCOMFORTABLE	1

HAVE TO WAR MORE MANAGEABLE CLOTHING	1
TRANSPORT & GETTING AROUND IS A PROBLEM	1
WANT MORE INFOMRATION	4
HARD TO ADMIT NEED FOR HELP	1
POWER IMBALANCE IN DR/PATIENT RELATIONSHIP	1
FEELING POWERLESS	1
WORRIED ABOUT FUTURE	1
FRIGHTENDIED THAT CONDITION WILL WORSEN	1
CAN'T DO SPORTING ACTIVITY	1
LOST STRENGTH, WEAKNESS	6
CHANGE TO SELF CONCEPT GOT ME DOWN I REALIZED I WAS POWERLESS	1
MAKES ME MENTALLY TOUGH	1
MAKES YOU MATURE	1
MAKES ME GLAD TO BE ALIVE	1
COULD BE WORSE	1
DEPRESSED	6
UNCERTAIN WHETHER CAN FACE DAILY ACTIVITIES	1
TRY TO BEAT IT	1
BORING	1
CAN'T GO DANCING	1
RESIGNED TO LIVING WITH IT, STOIC	2
HAVE TO ASK FOR TIME OFF WORK TO GO TO CLINIC	1
PHYSICAL MOBILITY	1
FIND OUT WHO YOUR FRIENDS ARE	1
BEEN A HELL OF A NUISANCE	1
FINANCIAL CONSTRAINTS AND EFFORT	2
FINANCES SLOWED BUSINESS DEVELOPMENT	1
HOPE TO DIE BEFORE GETTING TOO ILL	1
HOPE EUTHANASIA LEGALIZED	1

NORMATIVE REFERENTS

WIFE	2
I DO EXACTLY WHAT I WANT TO DO	1
MOTHER	1
PARENTS	1
DAUGHTER	4
CHURCH	1
HUSBAND	6
SON	4
KIDS, CHILDREN	5
DAUGHTER IN LAW	1
BROTHER SISTER	2
FAMILY	1
FRIENDS	7
COUSINS	1
AUNTS UNCLES	1
NEIGHBOURS	1
OLD WORKMATES	1
DOCTOR AT HOSPITAL	2
PHYSIO'S	1
DOG	1
ARTHRITIS FOUNDATION	1

SALIENT BELIEFS ELICITED FROM PERSONS WITH STROKE

LOST BALANCE	1
GAVE UP COFFEE, TEA, WORRY ABOUT DIET BEHAVIOR	3
CYNICAL ABOUT DEATH, FATALISTIC, NO CONTRC'L ANYWAY	1
MEMORY PROBLEMS	1
WORRY ABOUT MEDICATION	1
WORRY ABOUT HAVING MORE BLOODTESTS	1
BE CAREFUL OF ALCOHOL NOW	1
CAN'T DRIVE ANYMORE	1
DEPRESSED	1
FRUSTRATED	2
NEED SOMEONE TO TALK TO, CRY WITH	1
CAN'T DO WHAT I USED TO DO	1
NOT ENOUGH INFORMATION	1
DIAGNOSIS WAS DIFFICULT AND DELAYED	1
NO ADVANTAGES	2
REORGANIZED HOUSEWORK TO BE MANAGEABLE	1
NOTHING CHANGED (INITIAL COMMENT BUT THEN ID'D CHANGES)	1
HAD TO EASE UP AT GYM	1
I NEED COUNCIL HOME HELP	1
NEED TIME FOR MYSELF (PEOPLE ALWAYS AROUND)	1
WOULD PREFER TO DO THINGS FOR MYSELF, ESPECIALLY THINGS I USED TO DO	
AND TAKE PLEASURE IN	1
FAMILY RESPONSIBILITIES REORGANIZED	1
I NOW TAKE LIFE AS IT COMES	1
I HAVE TO TAKE TABLETS FOR THE REST OF MY LIFE	1
IT'S A SHOCK TO BE SICK/HARD TO ACCEPT	2
FRUSTRATED BY SPEECH PROBLEM	1
HARD TO MANAGE TO GET AROUND	1
WAS INDEPENDENT BUT NOT NOW	1
I WAS USED TO BEING THE STRONG ONE BUT NOW I'M NOT	1
HAVE TO ADMIT I'M SICK	1
I NOW THINK ABOUT THINGS BEFORE DOING THEM WEIGH UP PRO'S & CON'S OF ACTIVITY	2
I'M FRUSTRATED BY DOCTOR'S LACK OF APPARENT KNOWLEDGE	1
NEEDED CLEAR EXPLANATIONS	1
GOT CLEAR EXPLANATIONS	1
I NEED TO BE A MANLY MAN	1
ANNNOYED BY HOSPITAL INEFFICIENCY	1
ANNNOYED BY DOCTOR'S INEPTITUDE	1
HOSPITAL STAFF NEED MORE TECHNICAL TRAINING	1
I CAN'T BABY-SIT GRANDCHILDREN ANYMORE	1
I HAVE MORE TIME TO READ NOW	1
I ATTEND MALVERN DAY HOSPITAL	1
FATIGUE, PAIN, WEAKNESS, NUMBNESS	4
SOMETIMES CRY	1
HARD TO TALK ABOUT IT	1
CAN COOK A LITTLE	1
THINKING ABOUT A NURSING HOME, MOVED TO HOSTEL	2
POOR BALANCE	1
HARDER TO DO ODD JOBS, CHORES AT HOME	2
GAVE UP SAILING, BOCCI, CLAY SHOOTING	2
MAYBE WON'T GET BACK INTO COMMUNITY	1

DIFFICULTY WRITING (HANDWRITING)	2
DRIVING	2
RIDING PUSHBIKE	1
IT WAS DEPRESSING BUT I GOT OVER IT	1
THOUGHT I WAS GETTING OLDER, FALLING APART, GOING DOWNHILL	1
MAKES ME VULNERABLE AND HUMAN	1
RETHINK THE VALUE OF LIFE	1
RE-EVALUATE SELF & RELATIONSHIPS	1
MY WORK SUPERIORS MAY THINK I'M A LIABILITY	1
ANXIETY ABOUT HEALTH & SYMPTOMS	2
THINK ABOUT RETIREMENT NOW	1
ITS ROTTEN 'CPS ITS TOO SUDDEN & UNEXPECTED	1
I DON'T BELIEVE I HAD A STROKE	1
CAN'T ACCEPT I HAD A STROKE	1
BEING IN CONTROL (OF EVERYTHING AND MY LIFE) IS IMPORTANT	1
I HAVE FINANCIAL CONCERNs ABOUT RETIREMENT NOW	1
WORRIED ABOUT FUTURE PROGNOSIS, UNCERTAIN ABOUT FUTURE	3
DON'T WANT TO KNOW TOO MUCH ABOUT ILLNESS	1
NEED LOTS OF INFORMATION/LITERATURE	3
FEAR OF UNKNOWN	1
NEED EXPLANATION TO NEXT OF KIN	1
DIDN'T HAVE ANY HELP WITH INFO' GIVEN IN WORDS EG "WHAT'S A TIA?"	1
AT LEAST I KNOW I DIDN'T DIE	1
I NOW HAVE MORE UNDERSTANDING	1
NEW, DIFFERENT FRIENDS	1
I WAS AWARE AND TALKING	1
MORE PATIENCE NOW	1
I GAVE UP (ON LIFE)	1
GAVE UP WORK & WENT OF PENSION	1
LESS MOBILE (USING STICK), RESTRICTED MOVEMENT	3
GAVE UP EXECUTIVE POSTS AT VARIOUS CLUBS, CAN'T TAKE PART	1
DEMONSTRATED STOICISM	1

NORMATIVE REFERENTS

WIFE	5
HUSBAND	1
CHILDREN, DAUGHTER	6
FRIENDS, MATES	4
FATHER	1
I LISTEN TO MYSELF	1
NIECES, NEPHEWS	2
GRANDNIECES, GRANDCHILDREN	2
FAMILY	1
SISTER, BROTHERS	2
DOCTORS	1
SOCIAL CLUBS, ORGANIZATIONS (LIONS, PROBUS, MASONs)	3

SALIENT BELIEF ELICITED FROM PERSONS WITH DIABETES

NO ADVANTAGES	1
I HAD TO GIVE UP WORK	1
MONEY'S TIGHT ON A PENSION	1
CAN'T DO ANYTHING	1
LI'S BORING	1
CAN'T DO WHAT I USED TO DO (DANCE, WALK)	1
I WORRY ABOUT MY EYES GETTING WORSE	1
MY MEMORY IS NOT WHAT IT USED TO BE	1

MY EYESIGHT IS GOING	1
I'M OFF MY FOOD	1
I GET DOWNHEARTED WHEN I HAVE A SET BACK	1
SHOCKD BECAUSE NEVER BEEN SICK BEFORE	1
UNHAPPY	1
SICK OF TAKING TABLETS	1
I DID HAVE ENOUGH INFORMATION	1
STILL WORKING. IF I DIDN'T WORK I'D HAVE TOO MUCH TIME TO THINK THE	1
WORST	
WHAT WOULD I DO IF I GAVE UP WORK, WORK KEEPS MY MIND OCCUPIED	1
HEADACHES	
BEING ILL HAS TAUGHT ME TO LIVE DAY BY DAY	1
SHOCKED THAT I COULD BE BLIND	1
DEPRESSED WITH PROGNOSIS	1
RESIGNED TO ACCEPT THE FUTURE	1
DEMONSTRATED STOICISM	1

NORMATIVE REFERENNTS

MOEDICO'S, DOCTORS IN HOSPITAL	2
HUSBAND	1
CHILDREN	1
GP	1

APPENDIX F

PILOT STAGE LETTER, INFORMATION SHEET, CONSENT FORM AND QUESTIONNAIRES

THE ALFRED HEALTHCARE GROUP

Project title: An investigation and comparison of the psychosocial effects of chronic illness across three illness groups: The role of educational and psychological intervention.

Name(s) of researcher(s): Dr. Wally Kamilowicz
Kaylene J. Evers
Dr Duncan Topliss

EXPLANATORY STATEMENT: Stage 2+

You are invited to participate in this research project which aims to discover how people feel about coping with a chronic condition or illness on a daily basis. In particular, we hope to find out how these conditions may effect emotional and social well-being, and interactions with other people.

This stage of the research requires that you complete a questionnaire which has been developed as a result of finding out what is important to people with a chronic illness or condition. It will probably take about 20-30 minutes for you to complete the questionnaire. To be eligible you should be over 18 years of age and not have a concurrent diagnosis or medication regime which would influence results. Confirmation of these details will be made through medical records, with your approval. The information you supply will be anonymous, and no individual will be identified. The records will be kept in coded form for seven years following the completion of the research, after which time they will be destroyed. You are free to withdraw from the project at any time without prejudice to your continuing treatment.

If you would like information about the outcomes of the study please advise the researcher.

The ultimate aim is to develop a means of determining the needs of persons with chronic illness, and to develop a program of information and education which will then meet these identified needs. Some participants may be invited to take part in these informational and educational packages. All participants in this stage will be asked to complete the questionnaire a second time at a later date.

The research is conducted under the auspices of the hospital and Victoria University, Department of Psychology. The project is being conducted by Kaylene J. Evers, and is under the academic supervision of Dr. Wally Kamilowicz, and the professional supervision of Professor Susan Moore.

If you wish to discuss any matters concerning the project please speak to Kaylene Evers on 9365 2751 or contact Dr. Wally Kamilowicz on 9216 8106. To speak to a hospital representative about the project please contact Dr Duncan Topliss on 9276 2460

THANK YOU FOR YOUR PARTICIPATION

Chief researcher's signature:

Phone no(s):
9216 8106

THE ALFRED HEALTHCARE GROUP

Project Title: An investigation and comparison of the psychosocial effects of chronic illness across three illness groups: The role of educational and psychological intervention.

Names of researchers: Kaylene J Evers
Dr Adrian Fisher
Dr Duncan Topliss
Dr Judith Frayne
Dr Peter Ryan

EXPLANATORY STATEMENT: Stage 2+

You are invited to participate in this research project which aims to discover how people feel about coping with a chronic condition or illness on a daily basis. In particular, we hope to find out how these conditions may effect emotional and social well-being, and interactions with other people.

This stage of the research requires that you complete a questionnaire which has been developed as a result of finding out what is important to people with a chronic illness or condition. It will probably take about 20-30 minutes for you to complete the questionnaire. To be eligible you should be over 18 years of age and not have a concurrent diagnosis or medication regime which would influence results. Confirmation of these details will be made through medical records, with your approval. This information you supply will be anonymous, and no individual will be identified. The records will be kept in coded form for seven years following the completion of the research, after which time they will be destroyed. You are free to withdraw from the project at any time without prejudice to your continuing treatment.

If you would like information about the outcomes of the study please advise the researcher.

The ultimate aim is to develop a means of determining the needs of persons with chronic illness, and to develop a program of information and education which will then meet these identified needs. Some participants may be invited to take part in these informational and educational packages. All participants in this stage will be asked to complete the questionnaire a second time at a later date.

The research is conducted under the auspices of the hospital and Victoria University, Department of Psychology. The project is being conducted by Kaylene J. Evers, and is under the academic supervision of Dr Adrain Fisher .

If you wish to discuss any matters concerning the project please speak to Kaylene Evers on 9365 2336 or contact Dr Adrian Fisher. To speak to a hospital representative about the project please contact any of the Doctors listed on the previous .

THANKYOU FOR YOUR PARTICIPATION

Chief researchers signature:

A handwritten signature in black ink, appearing to read "Kaylene J. Evers".

THE ALFRED HEALTHCARE GROUP
Commercial Road, Prahran Victoria 3181

SUBJECT IDENTIFICATION
U.R. No.
NAME
ADDRESS.....
.....
DATE OF BIRTH.....

CONSENT FORM FOR RESEARCH PROJECT FOR COMPETENT SUBJECTS

PROJECT No. TITLE ..An investigation and comparison of the psychosocial effects of chronic illness across three illness groups: The role of educational and psychological intervention.....

CHIEF RESEARCHER ..Dr Wally Karnilowicz.....

- 1.I, the undersigned hereby consent to my involvement in the above research project.
- 2.I acknowledge that the nature, purpose and contemplated effects of the project so far as it affects me have been fully explained to my satisfaction by the researcher and my consent is given voluntarily.
- 3.I have received the Explanatory Statement and am familiar with the nature of the study including the anticipated length of time the study will take, the frequency with which visits and tests will be performed, and an indication of any discomfort which may be expected.
- 4.Although I understand that the purpose of this research project is to improve the quality of medical care, it has also been explained that my involvement may not be of any benefit to me.
- 5.I have been given the opportunity to have a member of my family or a friend present while the project was explained to me.
- 6.I have been informed that no information regarding my medical history will be divulged to unauthorised persons and that the results of any tests involving me will not be published in such a way as to reveal my identity.
- 7.I understand that my involvement in the project will not affect my relationship with my medical advisers in their management of my health. I also understand that I am free to withdraw from the project at any stage.
- 8.I confirm that it has been explained to me that the hospital has an Ethics Committee which:
 - (a) has approved the above project
 - (b) ensures that explanations such as I have received conform to ethical standards which this Hospital is required to observe, and
 - (c) has officers who may be authorised to contact me to check whether the proper standards are being observed and who are pledged to preserve the confidentiality of my involvement.

Signed..... this day/...../.....

Witness Name.....Signature..... this day/...../.....
Address.....

Researcher Name.....Signature.....

EXPLANATORY STATEMENT (Stage 2+):
AN INVESTIGATION AND COMPARISON OF THE PSYCHOSOCIAL
EFFECTS OF CHRONIC ILLNESS.

This research project is interested in how people feel about coping with a chronic condition or illness on a daily basis. In particular, how it may effect emotional and social well-being, and interactions with other people.

This stage of the research requires that you complete a questionnaire which has been developed as a result of finding out what is important to people with chronic illness. It will probably take about 20-30 minutes for you to complete the questionnaire. Participants will be excluded if they are not over 18 years of age or if they have a concurrent diagnosis or medication regime which would influence the results. Confirmation of these details will be made through medical records, with your approval. The information you supply will be anonymous in nature, and no individual will be identified. You are free to withdraw from the project at any time without prejudice.

If you would like information about the outcomes of the study please advise the researcher.

The ultimate aim is to develop a means of determining the needs of persons with chronic illness, and to develop a package of information and education addressing these needs. Some participants may be invited to take part in these informational and educational packages. All participants in this stage will be asked to complete the questionnaire a second time at a later date.

The research is conducted under the auspices of the hospital (*name of hospital*) and the Victoria University, Department of Psychology. The project is being conducted by Kaylene J. Evers, and is under the academic supervision of Dr. Wally Karnilowicz, and the professional supervision of Professor Susan Moore.

If you wish to discuss any matters concerning the project please speak to Kaylene Evers on 9365 2751 or contact Dr. Wally Karnilowicz on 9216 8106.

THANKYOU FOR YOUR PARTICIPATION

CONSENT FORM

TITLE OF PROJECT: An investigation and comparison of the psychosocial effects of chronic illness across three illness groups: the role of educational and psychological intervention.

1. INVESTIGATOR

I, Kaylene J. Evers have fully explained the aims, risks and procedures of the research project to.....

2. PARTICIPANT

I,.....(print name)

of.....(address)

agree to take part in the research project described in the attached explanation, being conducted by Kaylene J. Evers who has fully explained the research to me and given me a copy of the explanatory statement.

I understand that I am free to withdraw from the project at any time and I have the opportunity to have a friend or family member present while the project is explained to me.

Signed.....Date.....

I.....witness that the above consent has been given freely after due explanation of procedures.

Signed.....Date.....

Victoria University of Technology
McKechnie Street Telephone
St Albans (03) 9365 2111
PO Box 14428 Facsimile
M.C.M.C. (03) 9366 4852
Melbourne
Victoria 8001
Australia

St. Albans Campus

1



Dear Sir/Madam,

Thankyou for giving some of your time during 1996 to speak to me about your illness. The responses you gave then were pooled with those of other people from various hospitals. No individual was identified at any stage. However, you did give your name and address on the consent form you signed at the time. I would now like to check with you that the questionnaire I subsequently developed ,accurately reflects the issues which most people mentioned (although it may not contain all the issues which you personally identified). That is , I hope the questionnaire reflects the issues which were important to the majority of people. Your participation is strictly confidential and no individual will be identified. I now ask you to complete the attached questionnaire and return it to me as soon as possible. By taking the time to answer these questions you are helping add to a body of knowledge about chronic illness and its effects. Please retain the accompanying information sheet for your reference. If you would like information about the outcomes of the project please indicate your interest in writing and attach to the questionnaire.

Throughout please respond to questions as they apply to you personally.

THANKYOU FOR YOUR HELP AND CO-OPERATION

Sincerely,

Kaylene J. Evers

Please complete this section first.

Age _____ (in years) Year of birth _____

At what age did you first experience symptoms of your illness? _____

Please tick the appropriate box

What is your gender?

Male

Female

Do you live alone? Yes

No

If you do not live alone, do you share your residence with:

your children

your husband/wife/partner

your husband/wife/partner & child

parents

other (please state) _____

My primary diagnosis is:

Diabetes

Arthritis

Stroke

The illness or condition which I consider to have the effects which I am responding to in this questionnaire is:

Diabetes

Arthritis

Stroke

Are you currently taking medication? YES

NO

What kind of medication are you taking? _____

This week I am:

a. Driving a car

never	not often	neither	quite often	always
-------	-----------	---------	-------------	--------

b. using a walking stick

never	not often	neither	quite often	always
-------	-----------	---------	-------------	--------

c. using a walking frame

never	not often	neither	quite often	always
-------	-----------	---------	-------------	--------

d. in a wheelchair or a scooter

never	not often	neither	quite often	always
-------	-----------	---------	-------------	--------

e. bedbound

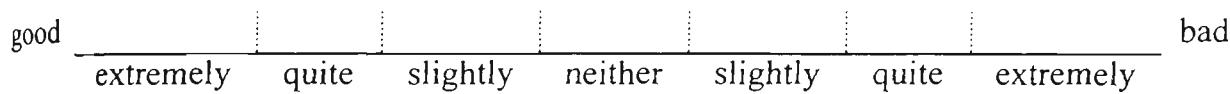
never	not often	neither	quite often	always
-------	-----------	---------	-------------	--------

How do you think your illness is effecting you today?

General Instructions

In the following sections of this questionnaire many questions make use of rating scales with seven places, you are to put a cross in the place that best describes your opinion. For example, if you were asked to rate "The weather in Melbourne" on such a scale, the seven places should be interpreted as follows:

The weather in Melbourne is:

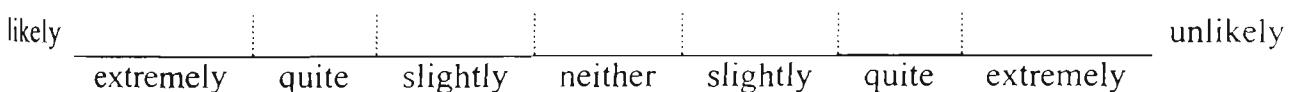


If you think the weather in Melbourne is *extremely good*, then you would place your mark as follows:

The weather in Melbourne is:

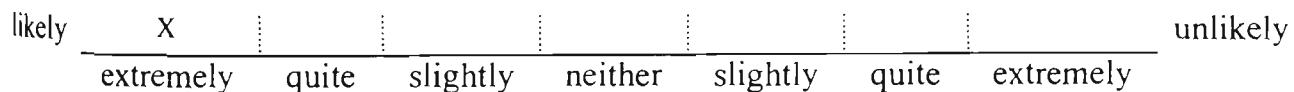


You will also be using a rating scale with Likely/Unlikely as endpoints. This scale is to be interpreted in the same way. For example, if you were asked to rate "The weather in Melbourne is hot in January" on such a scale, it would appear as follows:



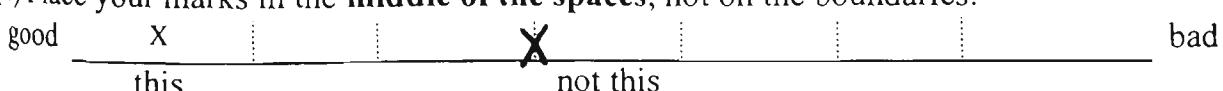
If you think it is *extremely likely* that the weather in Melbourne is hot in January,

then you would place your mark as follows:



In making your ratings, please remember the following points:

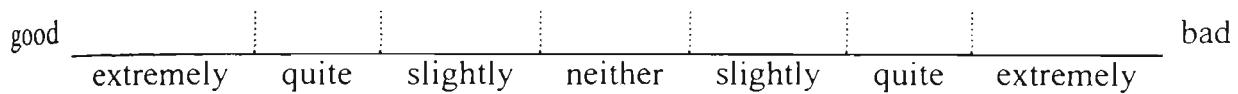
(1) Place your marks in the **middle of the spaces**, not on the boundaries:



(2) Never put more than one check mark on a single scale.

(3) FOR THE PURPOSE OF THIS RESEARCH PLEASE ANSWER ALL QUESTIONS. CONSIDER YOUR RESPONSES TO THE STATEMENT EVEN IF IT DOES NOT APPLY TO YOU NOW. THAT IS, IN EACH CASE CONSIDER IF IT WERE TRUE TO YOU, HOW WOULD YOU FEEL ABOUT IT?

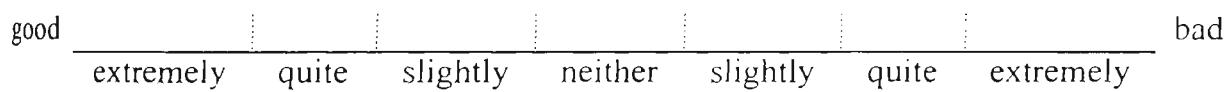
1. Having to cope with symptoms of my illness or condition is:



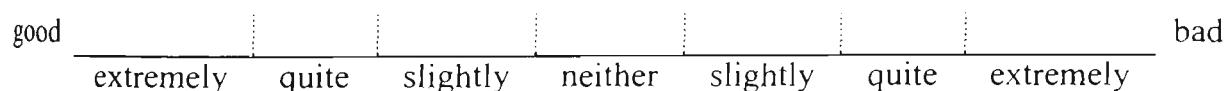
2. Not being able to do something like I used to do or want to do is :



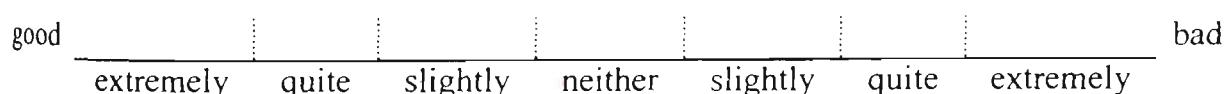
3. Being able to get around easily or as much as I want to is:



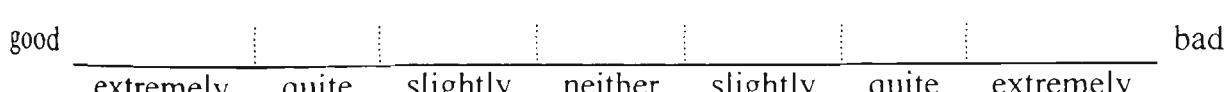
4. Being able to just put up with it or make the best of it is:



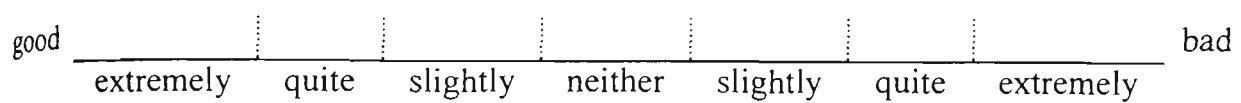
5. Having enough knowledge about this illness or condition is:



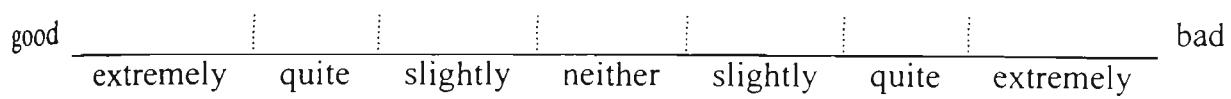
6. Being able to work is:



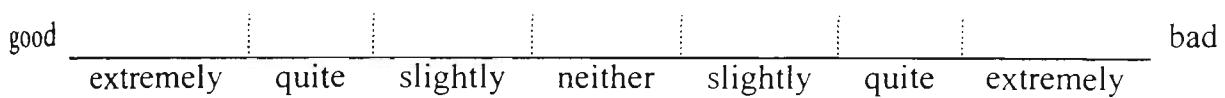
7. Changes to me that I think are an improvement to the type of person I think I am are:



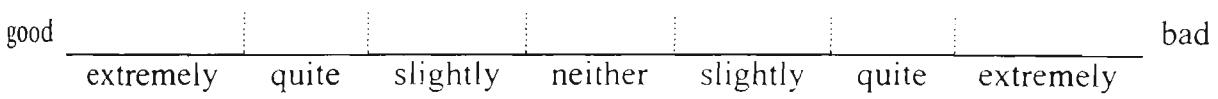
8. Having to be aware of my limitations and arrange things to accommodate my illness or condition is:



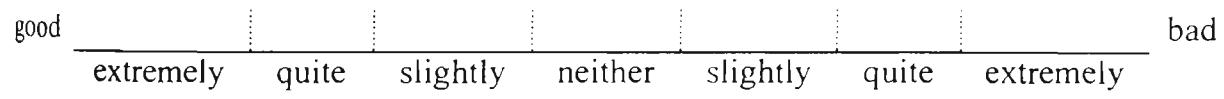
9. Changes that make me think I'm not the same person I used to be (changes to my concept of myself) are:



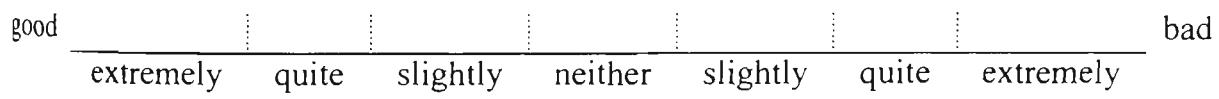
10. Having to rely on other people is :



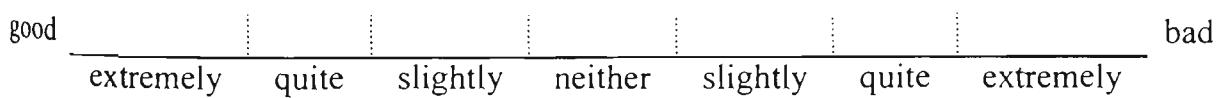
11. Being frustrated is:



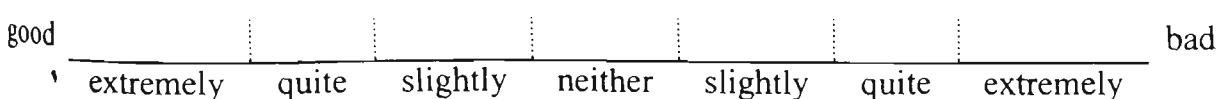
12. Having less power and control in my life is:



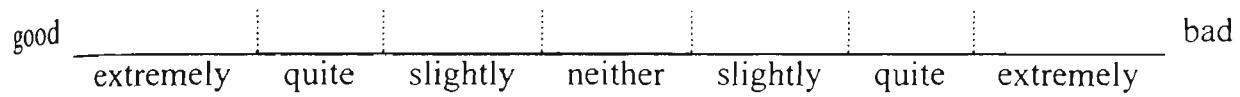
13. Feeling well taken care of by hospitals and doctors is:



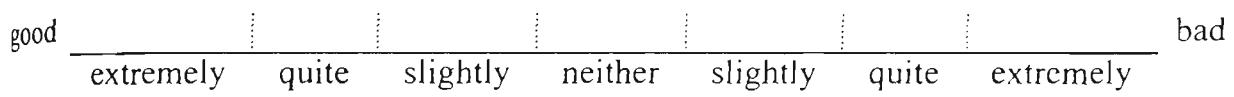
14. Being depressed is:



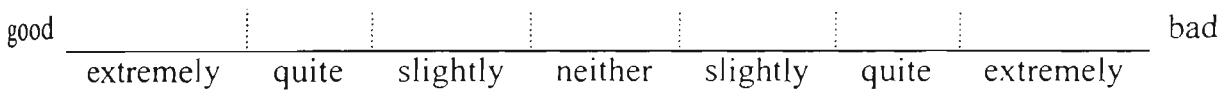
15. Making changes to my diet, smoking or drinking habits is:



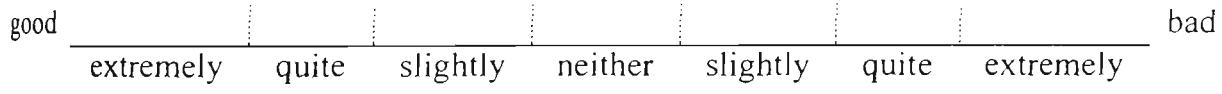
16. Being concerned about the future is:



17. Having the social support of the people around me is:

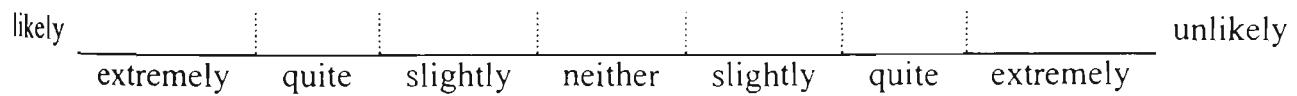


18. Having to cope with medications, equipment and treatment is:

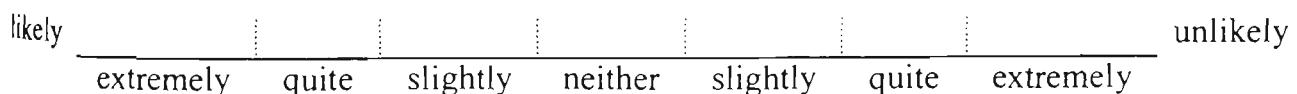


IN ANSWERING THE FOLLOWING QUESTIONS, PLEASE CONSIDER YOUR EXPERIENCE THIS WEEK.

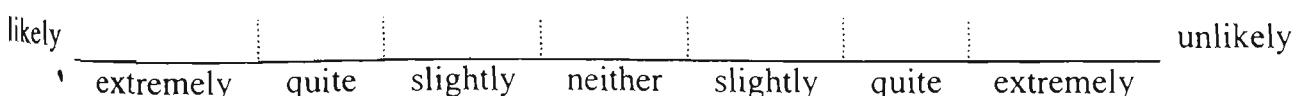
19. I will have to cope with symptoms of my illness or condition.



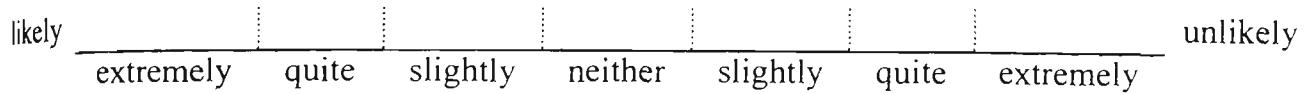
20. I will not be able to do something like I used to do or want to do.



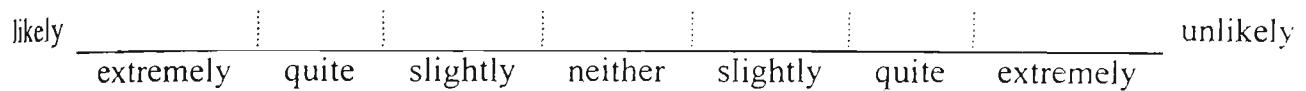
21. I will be able to get around easily or as much as I want to.



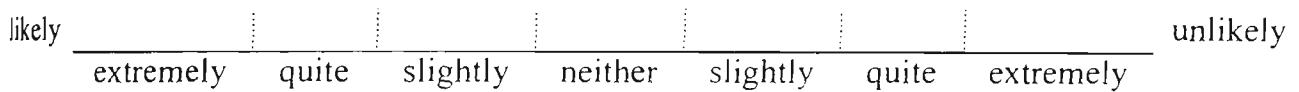
22. I will just put up with it or make the best of it.



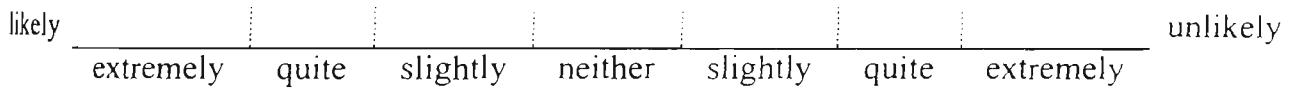
23. I will have enough knowledge about this illness or condition.



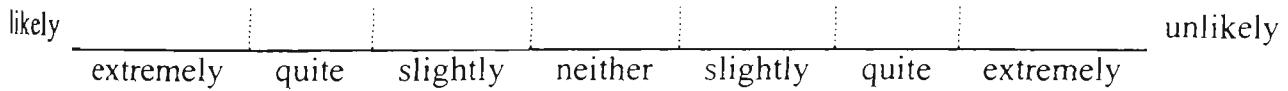
24. I will be able to work.



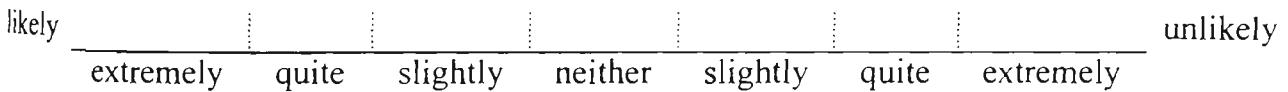
25. I will be changed in some way that is an improvement to the way I was before my illness.



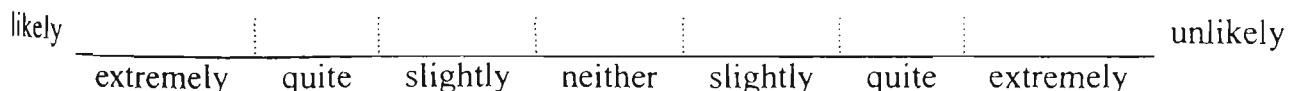
26. I will have to be aware of my limitations and arrange things to accommodate my illness or condition.

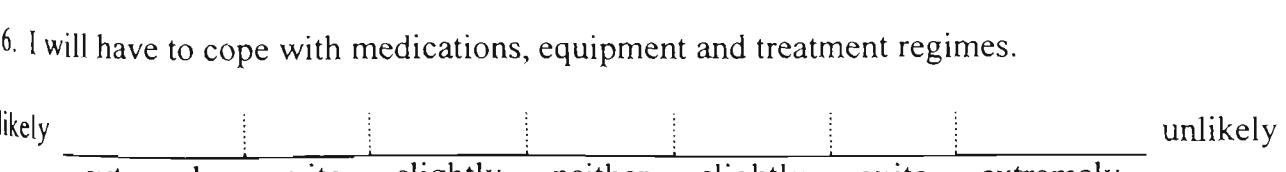
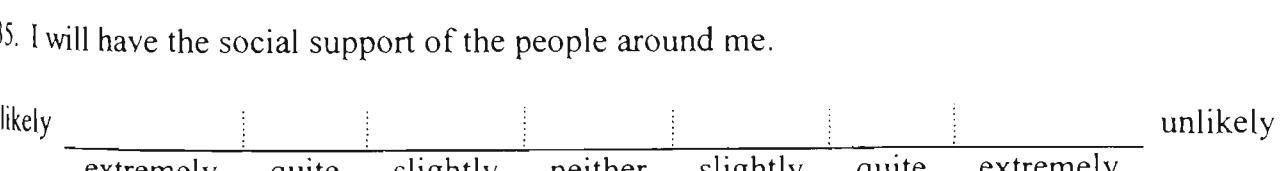
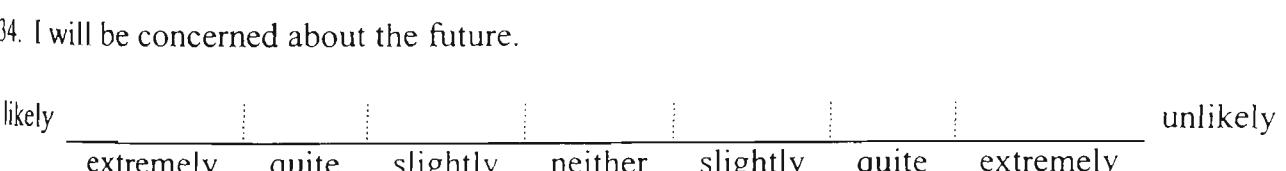
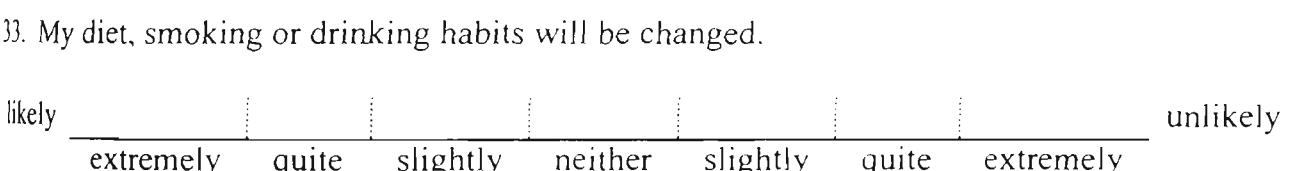
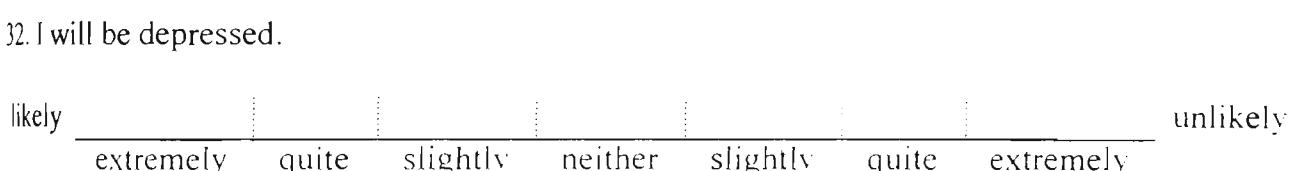
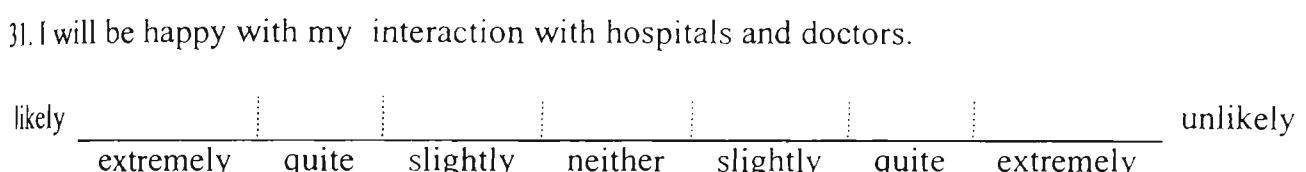
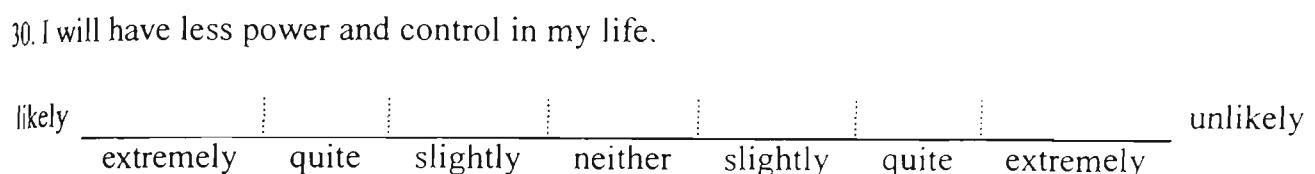
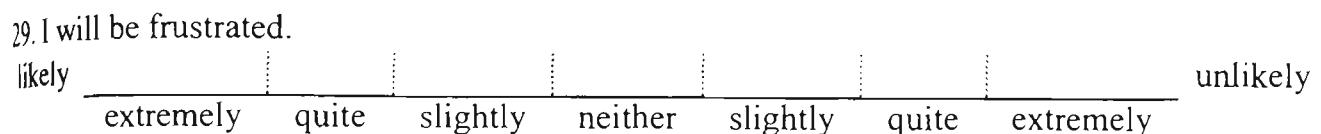


27. My idea of the person I am will be different to what it was before my illness or condition.

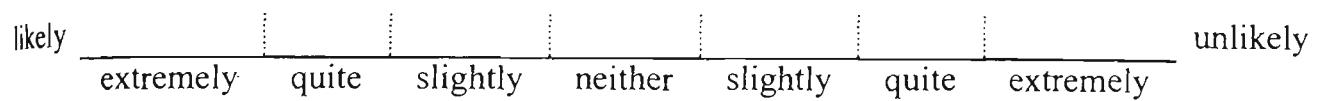


28. I will have to rely on other people in some way.

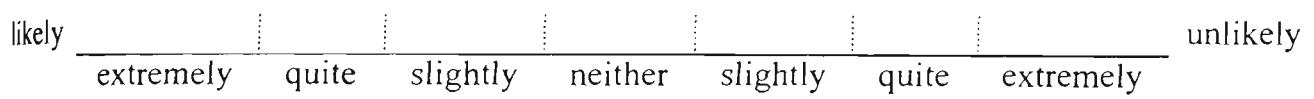




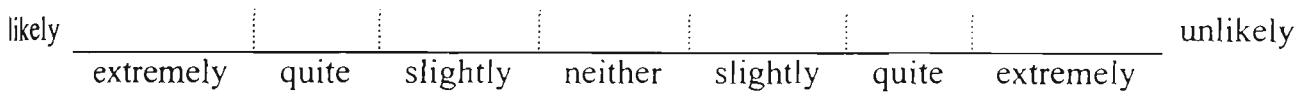
37. I have the support of my partner[spouse] this week.



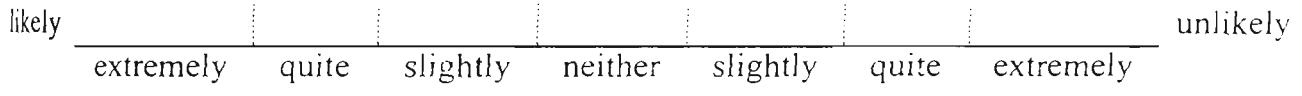
38. I do not have the support of my friends this week.



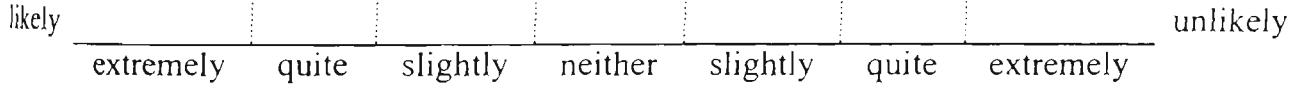
39. I have the support of my daughter (or daughter-in -law) this week.



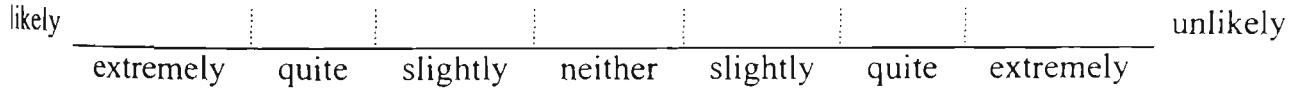
40. I have the support of my children this week.



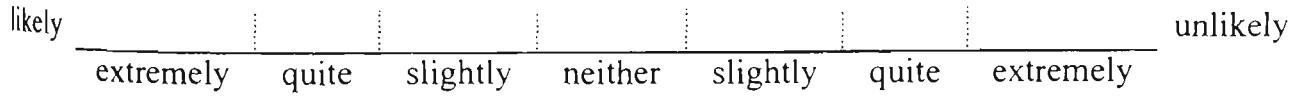
41. I have the support of the medical practitioners (doctors, nurses, physiotherapists etc.) this week.



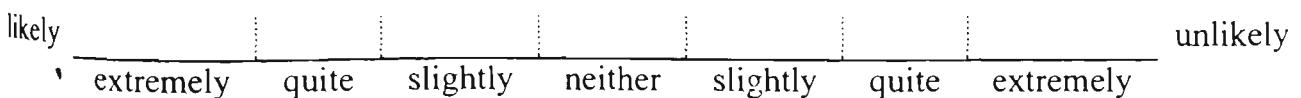
42. I have the support of my brother[s] and/or sister[s] this week.



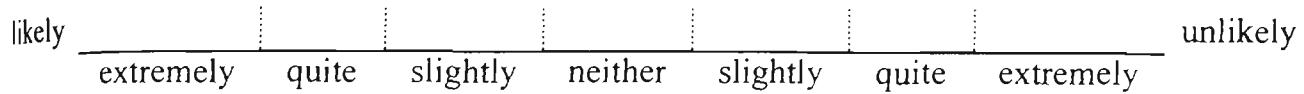
43. Generally speaking, I want to do what my partner [spouse] thinks I should do.



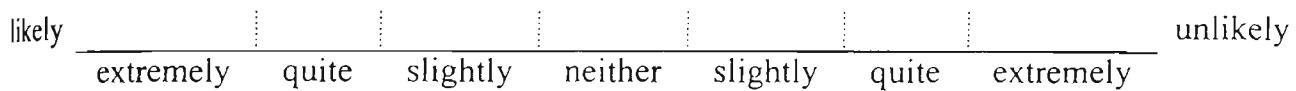
44. Generally speaking, I want to do what my friends think I should do.



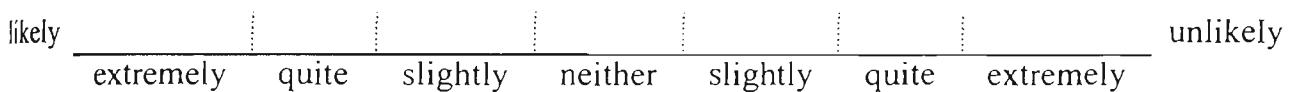
45. Generally speaking, I want to do what my daughter or [daughter in law] thinks I should do.



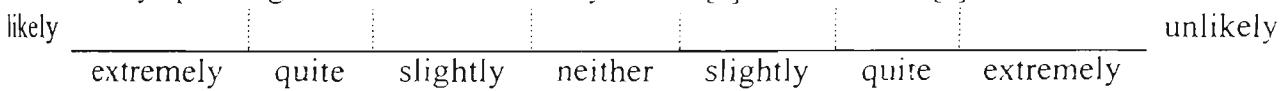
46. Generally speaking, I do not want to do what my children think I should do.



47. Generally speaking, I do not want to do what my doctors, nurses, physiotherapists etc. think I should do.



48. Generally speaking, I want to do what my brother[s] and /or sister[s] think I should do.



THANKYOU FOR YOUR HELP

APPENDIX G

WALLSTON'S HEALTH LOCUS OF CONTROL SCALE

MULTIDIMENSIONAL HEALTH LOCUS OF CONTROL SCALE (FORM B)

Name:

Date: Record Number:

This is a questionnaire designed to determine the way in which different people view certain important health-related issues. Each item is a belief statement with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you disagree or agree with the statement. The more strongly you agree with a statement, then the higher will be the number you circle. The more strongly you disagree with a statement, then the lower will be the number you circle. Please make sure that you answer every item and that you circle **only one** number per item. This is a measure of your personal beliefs: obviously, there are no right or wrong answers.

Please answer these items carefully, but do not spend too much time on any one item. As much as you can, try to respond to each item independently. When making your choice, do not be influenced by your previous choices. It is important that you respond according to your actual beliefs and not according to how you feel you should believe or how you think we want you to believe.

	Strongly disagree	Moderately disagree	Slightly disagree	Slightly agree	Moderately agree	Strongly agree
1. If I become sick, I have the power to make myself well again.	1	2	3	4	5	6
2. Often I feel that no matter what I do, if I am going to get sick, I will get sick.	1	2	3	4	5	6
3. If I see an excellent doctor regularly, I am less likely to have health problems.	1	2	3	4	5	6
4. It seems that my health is greatly influenced by accidental happenings.	1	2	3	4	5	6
5. I can only maintain my health by consulting health professionals.	1	2	3	4	5	6
6. I am directly responsible for my health.	1	2	3	4	5	6
7. Other people play a big part in whether I stay healthy or become sick.	1	2	3	4	5	6
8. Whatever goes wrong with my health is my own fault.	1	2	3	4	5	6
9. When I am sick, I just have to let nature run its course.	1	2	3	4	5	6
10. Health professionals keep me healthy.	1	2	3	4	5	6
11. When I stay healthy, I'm just plain lucky.	1	2	3	4	5	6
12. My physical well-being depends on how well I take care of myself.	1	2	3	4	5	6
13. When I feel ill, know it is because I have not been taking care of myself properly.	1	2	3	4	5	6
14. The type of care I receive from other people is what is responsible for how well I recover from an illness.	1	2	3	4	5	6
15. Even when I take care of myself, it's easy to get sick.	1	2	3	4	5	6
16. When I become ill, it's a matter of fate.	1	2	3	4	5	6
17. I can pretty much stay healthy by taking good care of myself.	1	2	3	4	5	6
18. Following doctor's orders to the letter is the best way for me to stay healthy.	1	2	3	4	5	6

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Code 4920 10 4



APPENDIX H

FINAL STAGE LETTER, INFORMATION SHEET, CONSENT FORM AND QUESTIONNAIRE

Victoria University of Technology

PO Box 14428
Melbourne City
MC 8001 Australia

Telephone:
(03) 9365 2111
Facsimile:
(03) 9366 4852

St Albans Campus
McKechnie Street
St Albans



Dear Sir/Madam,

This letter is to invite you to complete the attached questionnaire. I have attached an explanatory statement as well which will give you more details about the questionnaire. If you would like some help to complete it or you would like to discuss this with me, please feel free to ring me on 9365 2336 or 0416 226 906.

When you have completed the questionnaire please return it in the reply paid envelope provided.

Many thanks for your help and co-operation.

Best regards,



Kaylene Evers
PRINCIPAL RESEARCHER

THE ALFRED HEALTHCARE GROUP
Commercial Road, Prahran Victoria 3181

SUBJECT IDENTIFICATION
U.R. No.
NAME
ADDRESS.....
.....
DATE OF BIRTH.....

CONSENT FORM FOR RESEARCH PROJECT FOR COMPETENT SUBJECTS

PROJECT No. TITLE ..An investigation and comparison of the psychosocial effects of chronic illness across three illness groups: The role of educational and psychological intervention.....

CHIEF RESEARCHER ..Dr Wally Karnilowicz.....

1. I, the undersigned hereby consent to my involvement in the above research project.
2. I acknowledge that the nature, purpose and contemplated effects of the project so far as it affects me have been fully explained to my satisfaction by the researcher and my consent is given voluntarily.
3. I have received the Explanatory Statement and am familiar with the nature of the study including the anticipated length of time the study will take, the frequency with which visits and tests will be performed, and an indication of any discomfort which may be expected.
4. Although I understand that the purpose of this research project is to improve the quality of medical care, it has also been explained that my involvement may not be of any benefit to me.
5. I have been given the opportunity to have a member of my family or a friend present while the project was explained to me.
6. I have been informed that no information regarding my medical history will be divulged to unauthorised persons and that the results of any tests involving me will not be published in such a way as to reveal my identity.
7. I understand that my involvement in the project will not affect my relationship with my medical advisers in their management of my health. I also understand that I am free to withdraw from the project at any stage.
8. I confirm that it has been explained to me that the hospital has an Ethics Committee which:
 - (a) has approved the above project
 - (b) ensures that explanations such as I have received conform to ethical standards which this Hospital is required to observe, and
 - (c) has officers who may be authorised to contact me to check whether the proper standards are being observed and who are pledged to preserve the confidentiality of my involvement.

Signed this day/...../.....

Witness Name.....Signature..... this day/...../.....

Address.....

Researcher Name.....Signature.....

CONSENT FORM

TITLE OF PROJECT: An investigation and comparison of the psychosocial effects of chronic illness across three illness groups: the role of educational and psychological intervention.

1. INVESTIGATOR

I, Kaylene J. Evers have fully explained the aims, risks and procedures of the research project to.....

2. PARTICIPANT

I,.....(print name)

of.....(address)

agree to take part in the research project described in the attached explanation, being conducted by Kaylene J. Evers who has fully explained the research to me and given me a copy of the explanatory statement.

I understand that I am free to withdraw from the project at any time and I have the opportunity to have a friend or family member present while the project is explained to me.

Signed.....Date.....

I.....witness that the above consent has been given freely after due explanation of procedures.

Signed.....Date.....

Please complete this section first.

Age _____ (in years) Year of birth _____

At what age did you first experience symptoms of your illness? _____

Please tick the appropriate box

What is your gender?

Male

Female

Do you live alone? Yes

No

If you do not live alone, do you share your residence with:

your children

your husband/wife/partner

your husband/wife/partner & child

parents

other (please state) _____

My primary diagnosis is:

Diabetes Arthritis Stroke

The illness or condition which I consider to have the effects which I am responding to in this questionnaire is:

Diabetes Arthritis Stroke

Are you currently taking medication? YES

NO

What kind of medication are you taking? _____

This week I am:

1. Driving a car

never : not often : neither : quite often : always

b. using a walking stick

c. using a walking frame

d. in a wheelchair or a scooter

never	not often	neither	quite often	always
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e. bedbound

never	not often	neither	quite often	always
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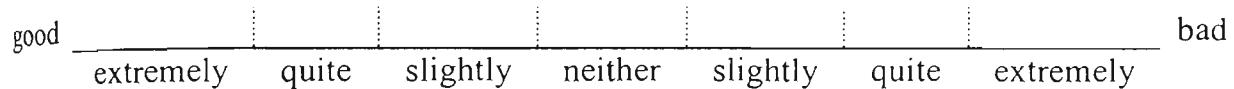
How do you think your illness is effecting you today?

Digitized by srujanika@gmail.com

General Instructions

In the following sections of this questionnaire many questions make use of rating scales with seven places; you are to put a cross in the place that best describes your opinion. For example, if you were asked to rate "The weather in Melbourne" on such a scale, the seven places should be interpreted as follows:

The weather in Melbourne is:

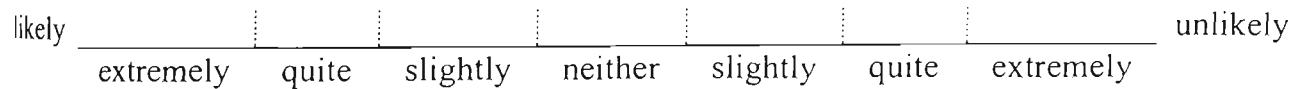


If you think the weather in Melbourne is *extremely good*, then you would place your mark as follows:

The weather in Melbourne is:

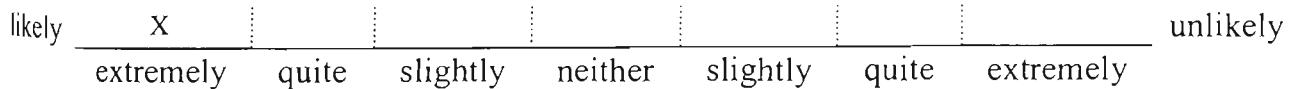


You will also be using a rating scale with Likely/Unlikely as endpoints. This scale is to be interpreted in the same way. For example, if you were asked to rate "The weather in Melbourne is hot in January" on such a scale, it would appear as follows:



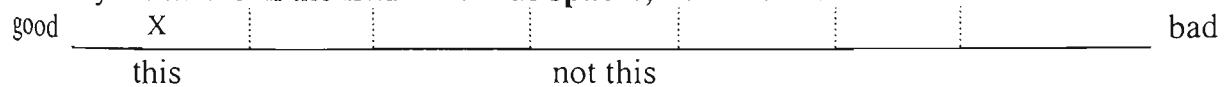
If you think it is *extremely likely* that the weather in Melbourne is hot in January,

then you would place your mark as follows:



In making your ratings, please remember the following points:

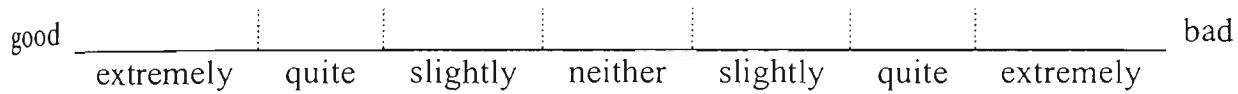
(1) Place your marks in the **middle of the spaces**, not on the boundaries:



(2) Never put more than one check mark on a single scale.

(3) FOR THE PURPOSE OF THIS RESEARCH PLEASE ANSWER ALL QUESTIONS. CONSIDER YOUR RESPONSES TO THE STATEMENT EVEN IF IT DOES NOT APPLY TO YOU NOW. THAT IS, IN EACH CASE CONSIDER IF IT WERE TRUE TO YOU, HOW WOULD YOU FEEL ABOUT IT?

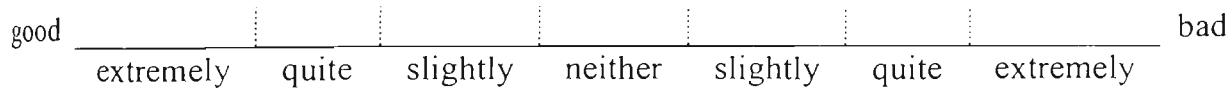
1. Having to cope with symptoms of my illness or condition is:



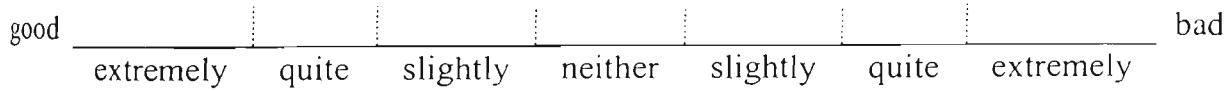
2. Not being able to do something like I used to do or want to do is :



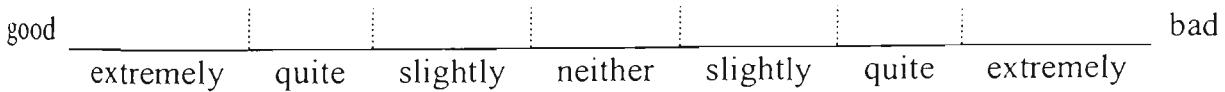
3. Being able to get around easily or as much as I want to is:



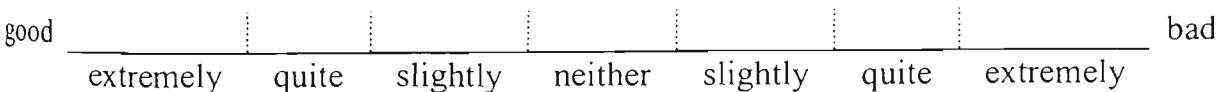
4. Being able to just put up with it or make the best of it is:



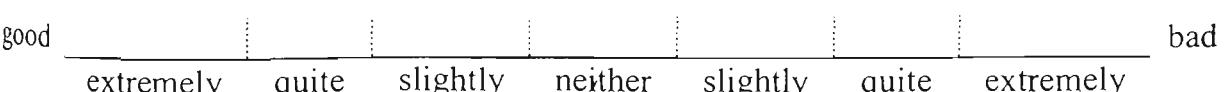
5. Having enough knowledge about this illness or condition is:



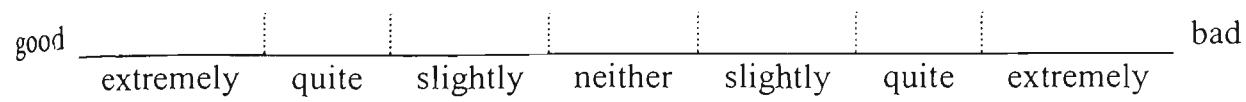
6. Being able to work is:



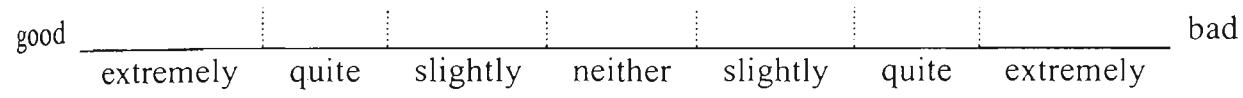
7. Changes to me that I think are an improvement to the type of person I think I am are:



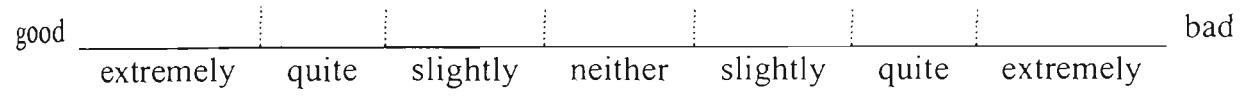
8. Having to be aware of my limitations and arrange things to accommodate my illness or condition is:



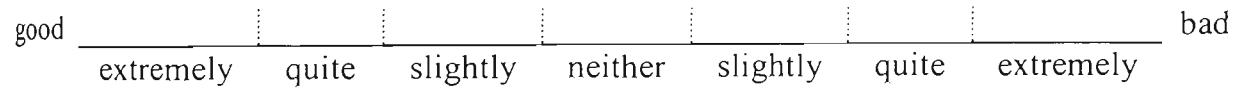
9. Changes that make me think I'm not the same person I used to be (changes to my concept of myself) are:



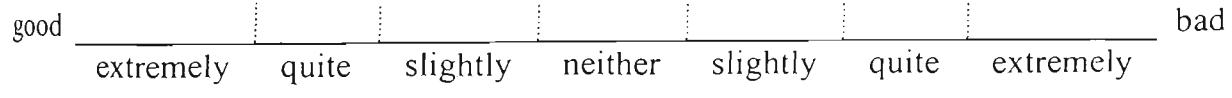
10. Having to rely on other people is :



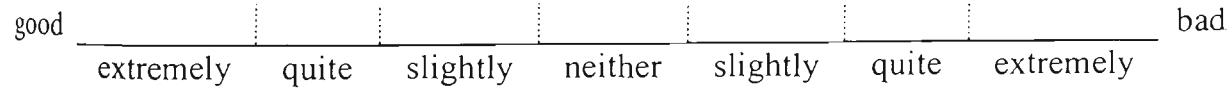
11. Being frustrated is:



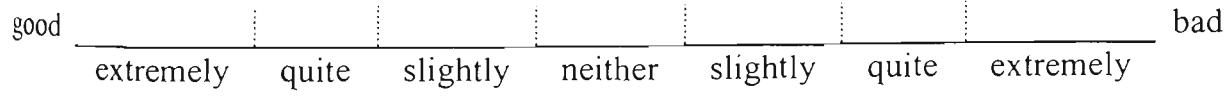
12. Having less power and control in my life is:



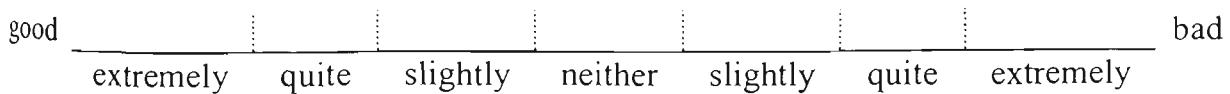
13. Feeling well taken care of by hospitals and doctors is:



14. Being depressed is:



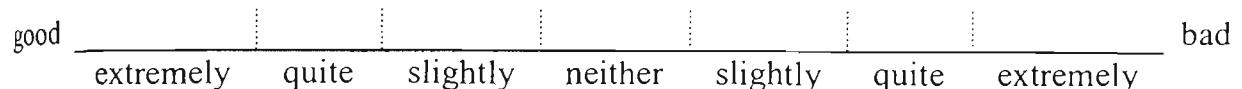
15. Making changes to my diet, smoking or drinking habits is:



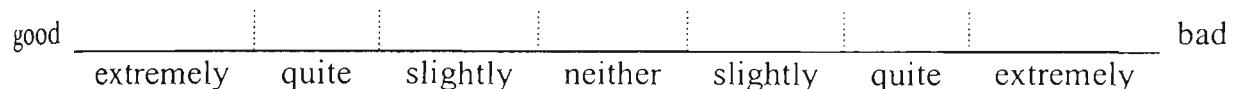
16. Being concerned about the future is:



17. Having the social support of the people around me is:

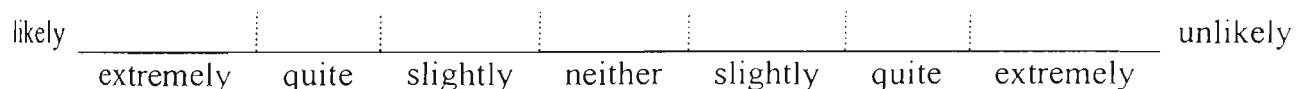


18. Having to cope with medications, equipment and treatment is:

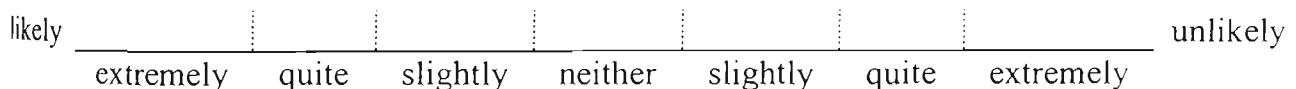


IN ANSWERING THE FOLLOWING QUESTIONS, PLEASE CONSIDER YOUR EXPERIENCE THIS WEEK.

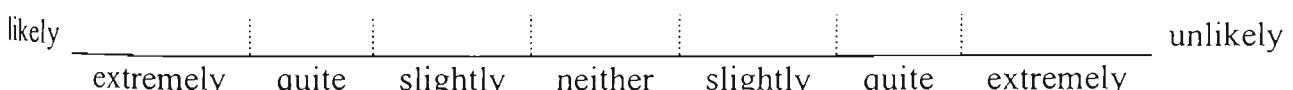
19. I will have to cope with symptoms of my illness or condition.



20. I will not be able to do something like I used to do or want to do.



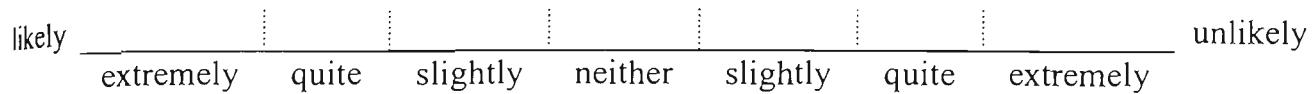
21. I will be able to get around easily or as much as I want to.



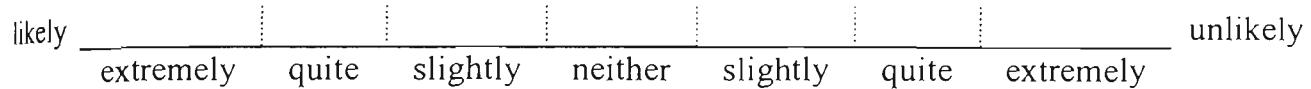
22. I will just put up with it or make the best of it.



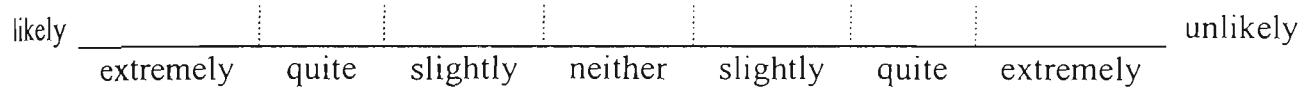
23. I will have enough knowledge about this illness or condition.



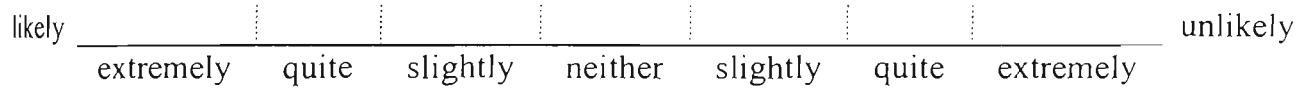
24. I will be able to work.



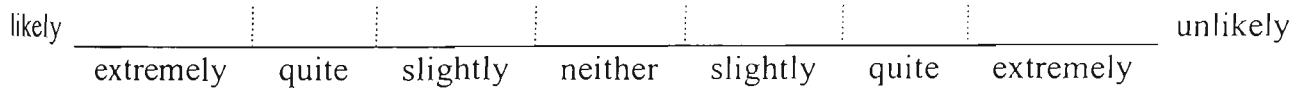
25. I will be changed in some way that is an improvement to the way I was before my illness.



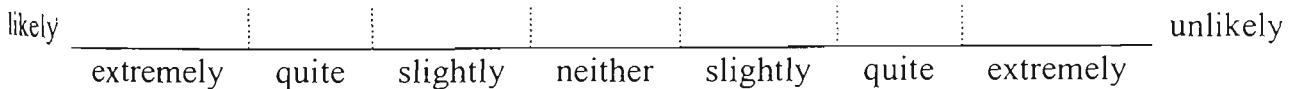
26. I will have to be aware of my limitations and arrange things to accommodate my illness or condition.



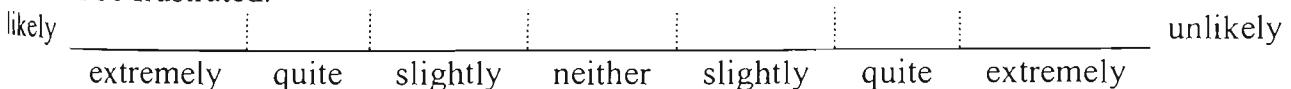
27. My idea of the person I am will be different to what it was before my illness or condition.



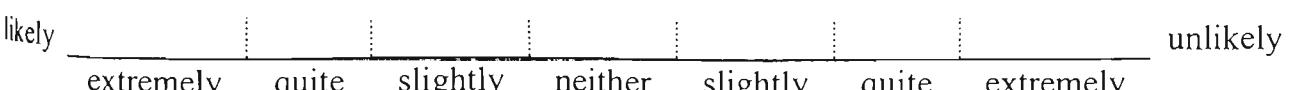
28. I will have to rely on other people in some way.



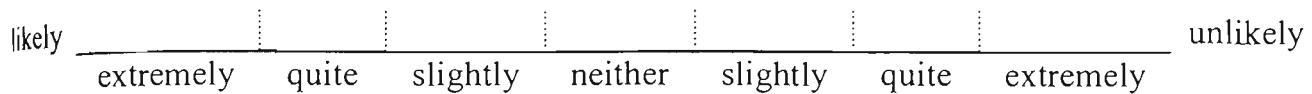
29. I will be frustrated.



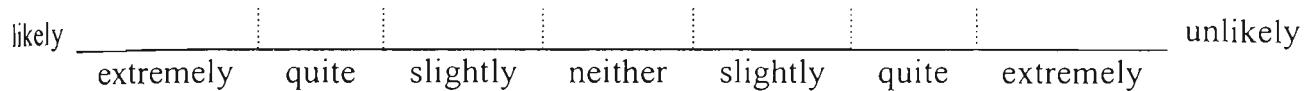
30. I will have less power and control in my life.



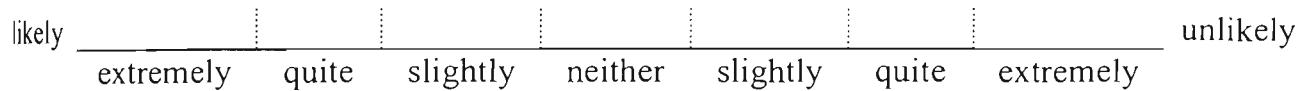
31. I will be happy with my interaction with hospitals and doctors.



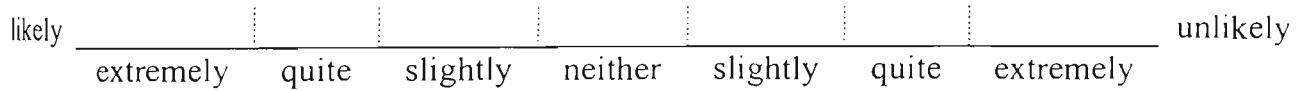
32. I will be depressed.



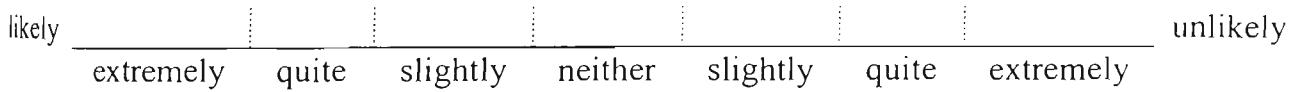
33. My diet, smoking or drinking habits will be changed.



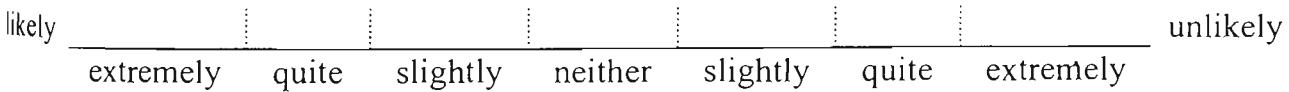
34. I will be concerned about the future.



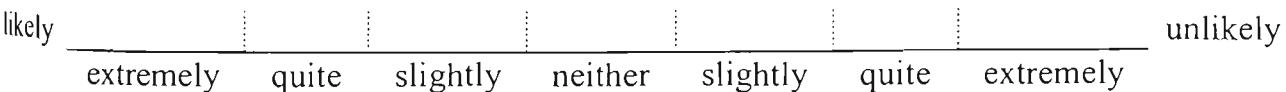
35. I will have the social support of the people around me.



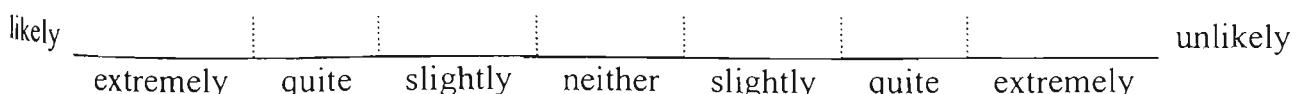
36. I will have to cope with medications, equipment and treatment regimes.



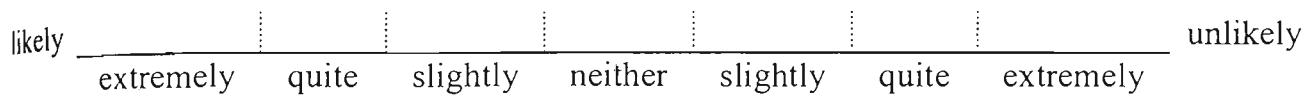
37. I have the support of my partner[spouse] this week.



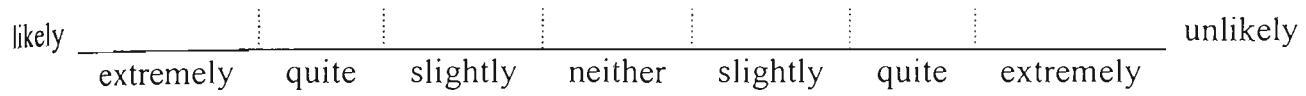
38. I do not have the support of my friends this week.



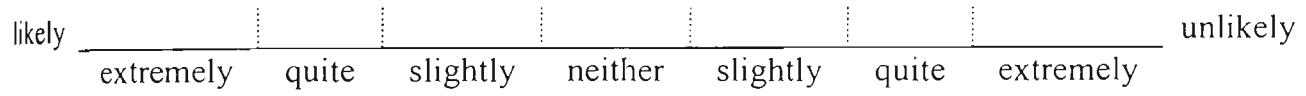
39. I have the support of my daughter (or daughter-in -law) this week.



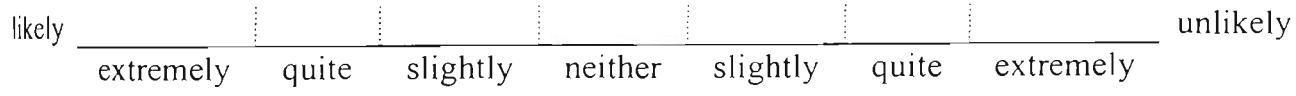
40. I have the support of my children this week.



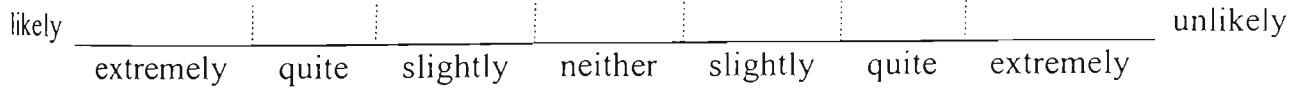
41. I have the support of the medical practitioners (doctors, nurses, physiotherapists etc.) this week.



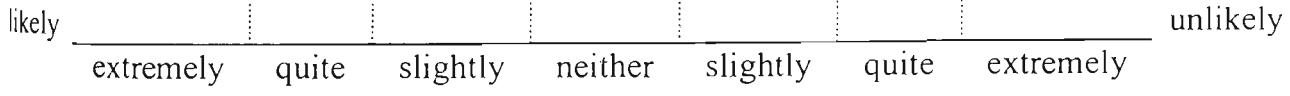
42. I have the support of my brother[s] and/or sister[s] this week.



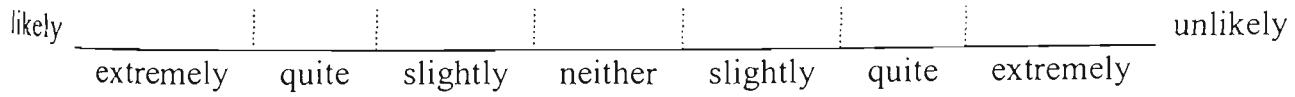
43. Generally speaking, I want to do what my partner [spouse] thinks I should do.



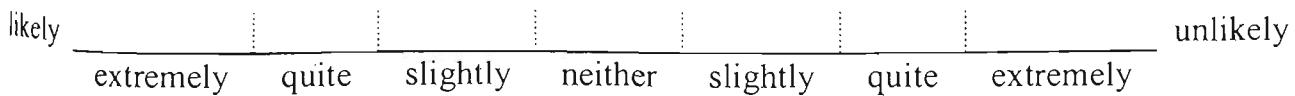
44. Generally speaking, I want to do what my friends think I should do.



45. Generally speaking, I want to do what my daughter or [daughter in law] thinks I should do.



46. Generally speaking, I do not want to do what my children think I should do.



47. Generally speaking, I do not want to do what my doctors, nurses, physiotherapists etc. think I should do.

likely	extremely	quite	slightly	neither	slightly	quite	extremely	unlikely
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48. Generally speaking, I want to do what my bother[s] and /or sister[s] think I should do.

likely	extremely	quite	slightly	neither	slightly	quite	extremely	unlikely
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Section 2: Beliefs about health. .

This is a questionnaire designed to determine the way in which different people view certain important health-related issues. Each item is a belief statement with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you disagree or agree with the statement. The more strongly you agree with a statement, then the higher will be the number you circle. The more strongly you disagree with a statement, then the lower will be the number you circle. Please make sure that you answer every item and that you circle **only one** number per item. This is a measure of your personal beliefs: obviously, there are no right or wrong answers.

Please answer these items carefully, but do not spend too much time on any one item. As much as you can, try to respond to each item independently. When making your choice, do not be influenced by your previous choices. It is important that you respond according to your actual beliefs and not according to how you feel you should believe or how you think we want you to believe.

Strongly disagree	Moderately disagree	Slightly disagree	Slightly agree	Moderately agree	Strongly agree
----------------------	------------------------	----------------------	-------------------	---------------------	-------------------

- | | | | | | | |
|---|---|---|---|---|---|---|
| 1. If I become sick, I have the power to make myself well again. | 1 | 2 | 3 | 4 | 5 | 6 |
| 2. Often I feel that no matter what I do, if I am going to get sick, I will get sick. | 1 | 2 | 3 | 4 | 5 | 6 |
| 3. If I see an excellent doctor regularly, I am less likely to have health problems. | 1 | 2 | 3 | 4 | 5 | 6 |
| 4. It seems that my health is greatly influenced by accidental happenings. | 1 | 2 | 3 | 4 | 5 | 6 |
| 5. I can only maintain my health by consulting health professionals. | 1 | 2 | 3 | 4 | 5 | 6 |
| 6. I am directly responsible for my health. | 1 | 2 | 3 | 4 | 5 | 6 |
| 7. Other people play a big part in whether I stay healthy or become sick. | 1 | 2 | 3 | 4 | 5 | 6 |
| 8. Whatever goes wrong with my health is my own fault. | 1 | 2 | 3 | 4 | 5 | 6 |
| 9. When I am sick, I just have to let nature run its course. | 1 | 2 | 3 | 4 | 5 | 6 |
| 10. Health professionals keep me healthy. | 1 | 2 | 3 | 4 | 5 | 6 |
| 11. When I stay healthy, I'm just plain lucky. | 1 | 2 | 3 | 4 | 5 | 6 |
| 12. My physical well-being depends on how well I take care of myself. | 1 | 2 | 3 | 4 | 5 | 6 |
| 13. When I feel ill, know it is because I have not been taking care of myself properly. | 1 | 2 | 3 | 4 | 5 | 6 |
| 14. The type of care I receive from other people is what is responsible for how well I recover from an illness. | 1 | 2 | 3 | 4 | 5 | 6 |
| 15. Even when I take care of myself, it's easy to get sick. | 1 | 2 | 3 | 4 | 5 | 6 |
| 16. When I become ill, it's a matter of fate. | 1 | 2 | 3 | 4 | 5 | 6 |
| 17. I can pretty much stay healthy by taking good care of myself. | 1 | 2 | 3 | 4 | 5 | 6 |
| 18. Following doctor's orders to the letter is the best way for me to stay healthy. | 1 | 2 | 3 | 4 | 5 | 6 |

1. Generally speaking, I do not want to do what my doctors, nurses, physiotherapists etc. think I should do.

likely	extremely	quite	slightly	neither	slightly	quite	extremely	unlikely
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18. Generally speaking, I want to do what my brother[s] and /or sister[s] think I should do.

likely	extremely	quite	slightly	neither	slightly	quite	extremely	unlikely
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Section 2: Beliefs about health.

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Please answer these items carefully, but do not spend too much time on any one item. As much as you can, try to respond to each item independently. When making your choice, do not be influenced by your previous choices. It is important that you respond according to your actual beliefs and not according to how you feel you should believe or how you think we want you to believe.

Strongly disagree	Moderately disagree	Slightly disagree	Slightly agree	Moderately agree	Strongly agree
----------------------	------------------------	----------------------	-------------------	---------------------	-------------------

- | | | | | | | |
|---|---|---|---|---|---|---|
| 1. If I become sick, I have the power to make myself well again. | 1 | 2 | 3 | 4 | 5 | 6 |
| 2. Often I feel that no matter what I do, if I am going to get sick, I will get sick. | 1 | 2 | 3 | 4 | 5 | 6 |
| 3. If I see an excellent doctor regularly, I am less likely to have health problems. | 1 | 2 | 3 | 4 | 5 | 6 |
| 4. It seems that my health is greatly influenced by accidental happenings. | 1 | 2 | 3 | 4 | 5 | 6 |
| 5. I can only maintain my health by consulting health professionals. | 1 | 2 | 3 | 4 | 5 | 6 |
| 6. I am directly responsible for my health. | 1 | 2 | 3 | 4 | 5 | 6 |
| 7. Other people play a big part in whether I stay healthy or become sick. | 1 | 2 | 3 | 4 | 5 | 6 |
| 8. Whatever goes wrong with my health is my own fault. | 1 | 2 | 3 | 4 | 5 | 6 |
| 9. When I am sick, I just have to let nature run its course. | 1 | 2 | 3 | 4 | 5 | 6 |
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| 11. When I stay healthy, I'm just plain lucky. | 1 | 2 | 3 | 4 | 5 | 6 |
| 12. My physical well-being depends on how well I take care of myself. | 1 | 2 | 3 | 4 | 5 | 6 |
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| 14. The type of care I receive from other people is what is responsible for how well I recover from an illness. | 1 | 2 | 3 | 4 | 5 | 6 |
| 15. Even when I take care of myself, it's easy to get sick. | 1 | 2 | 3 | 4 | 5 | 6 |
| 16. When I become ill, it's a matter of fate. | 1 | 2 | 3 | 4 | 5 | 6 |
| 17. I can pretty much stay healthy by taking good care of myself. | 1 | 2 | 3 | 4 | 5 | 6 |
| 18. Following doctor's orders to the letter is the best way for me to stay healthy. | 1 | 2 | 3 | 4 | 5 | 6 |

APPENDIX I

MEANS AND STANDARD DEVIATIONS OF ATTITUDINAL COMPONENTS AND NORMATIVE REFERENTS

Means And Standard Deviations Of Attitudinal Components And Normative Referents

primary diagnosis		Mean	Std. Deviation
	diabetes		
	coping with symptoms	.42	4.14
	not doing what used to do or want to do	-.31	4.07
	mobility	-1.45	4.58
	being stoic	-.92	3.88
	sufficient knowledge re: illness	4.21	3.41
	working	3.81	4.71
	positive changes to self concept	.65	5.86
	accommodating illness and limitations	-.27	4.56
	changed self concept	-.65	4.23
	reliance on others	-1.05	3.96
	being frustrated	-2.84	4.40
	reduced self efficacy	-2.47	3.71
	feeling well cared for by medicos	4.92	3.74
	being depressed	-1.65	4.52
	lifestyle changes; diet, smoking, drinking	.63	4.84
	concern about future	-.74	4.27
	social support	4.45	3.36
	coping with medical technology	1.55	4.42
	arthritis		
	coping with symptoms	-1.34	5.45
	not doing what used to do or want to do	-3.60	4.61
	mobility	-1.14	5.03
	being stoic	-.44	4.43
	sufficient knowledge re: illness	4.01	4.35
	working	2.22	5.48
	positive changes to self concept	.25	3.22
	accommodating illness and limitations	.58	5.22
	changed self concept	-2.09	3.54
	reliance on others	-3.46	4.29
	being frustrated	-3.98	3.58
	reduced self efficacy	-2.49	4.92
	feeling well cared for by medicos	3.91	3.55
	being depressed	-.64	4.46
	lifestyle changes; diet, smoking, drinking	-.36	4.17
	concern about future	-1.62	4.58
	social support	3.35	4.72
	coping with medical technology	.40	5.64
	stroke		
	coping with symptoms	-1.18	3.54
	not doing what used to do or want to do	-.94	4.36
	mobility	-1.18	4.74
	being stoic	-1.18	3.59

	sufficient knowledge re:illness	4.06	2.45
	working	1.44	5.06
	positive changes to self concept	-.12	3.18
	accommodating illness and limitations	.32	4.50
	changed self concept	-.44	3.89
	reliance on others	-1.32	3.41
	being frustrated	.50	4.92
	reduced self efficacy	.24	5.33
	feeling well cared for by medicos	4.09	3.58
	being depressed	.50	4.47
	lifestyle changes; diet ,smoking, drinking	-.21	3.70
	concern about future	-1.85	3.46
	social support	4.12	3.02
	coping with medical technology	-.91	4.51
Total	coping with symptoms	-.71	4.76
	not doing what used to do or want to do	-1.97	4.63
	mobility	-1.25	4.80
	being stoic	-.74	4.09
	sufficient knowledge re: illness	4.09	3.72
	working	2.62	5.20
	positive changes to self concept	.31	4.29
	accommodating illness and limitations	.24	4.86
	changed self concept	-1.29	3.91
	reliance on others	-2.23	4.17
	being frustrated	-2.75	4.44
	reduced self efficacy	-1.97	4.72
	feeling well cared for by medicos	4.29	3.63
	being depressed	-.77	4.52
	lifestyle changes; diet ,smoking, drinking	5.52E-03	4.33
	concern about future	-1.36	4.29
	social support	3.87	4.02
	coping with medical technology	.55	5.09

APPENDIX J

STRUCTURE CORRELATIONS FOR DEPENDENT VARIABLES IN DISCRIMINANT FUNCTION ANALYSIS

Structure Correlations For Dependent Variables In Discriminant Function Analysis

	Coping with symptoms what used to do or want to do	Not doing mobility what used to do or want to do	Being stoic re: illness	Sufficient knowledge re: illness	Working	Positive changes to self concept	Accommodating illness and limitations	Changed self concept	Reliance on others	Being trusted rated	Reduced self efficacy	Feeling well cared for by medicos	Being depressed	Lifestyle changes; diet, smoking, drinking	Concern about future	Social support	Coping with medical technology	
coping with symptoms not doing what used to do or want to do	.1,000	.271	.041	-.170	.042	.220	-.077	.292	.168	.346	.262	.275	.263	.112	.108	.350	.136	.563
not doing what used to do or want to do	.271	1,000	-.097	-.027	.119	-.161	-.300	.349	.219	.315	.270	.287	.085	.258	-.040	.354	.058	.182
mobility being stoic sufficient knowledge re: illness	.041	-.097	1,000	.157	.079	.083	-.126	-.070	.054	-.108	-.101	-.002	-.096	-.122	.184	.091	-.127	.026
being stoic sufficient knowledge re: illness	-.170	-.027	.157	1,000	-.086	-.086	-.247	-.346	-.109	-.254	-.208	-.300	-.235	-.041	-.213	-.116	-.049	-.346
working positive changes to self concept	.042	.119	.079	-.086	1,000	.048	-.034	.042	.019	.026	.037	.039	.252	.275	.067	.143	.143	.112
accommodating illness and limitations changed self concept	.220	-.077	-.300	-.126	-.247	-.034	.107	1,000	.107	.007	-.109	.202	.159	.240	-.094	.107	.004	.174
changed self concept reliance on others being frustrated reduced self efficacy feeling well cared for by medicos being depressed lifestyle changes; diet, smoking, drinking	.292	.349	-.070	-.346	.042	.007	.052	1,000	.052	.053	.001	.148	.104	.175	-.036	.218	-.037	.062
reliance on others being frustrated reduced self efficacy feeling well cared for by medicos being depressed lifestyle changes; diet, smoking, drinking concern about future social support coping with medical technology	.168	.219	.054	-.109	.019	-.109	.053	.397	1,000	.381	.317	.227	.080	.236	.018	.410	.026	.106
being frustrated reduced self efficacy feeling well cared for by medicos being depressed lifestyle changes; diet, smoking, drinking concern about future social support coping with medical technology	.346	.315	-.108	-.254	.026	.202	.001	.385	.381	1,000	.487	.535	.095	.328	.127	.325	.093	.219
being frustrated reduced self efficacy feeling well cared for by medicos being depressed lifestyle changes; diet, smoking, drinking concern about future social support coping with medical technology	.262	.270	-.101	-.208	-.037	.159	.148	.321	.317	.487	1,000	.690	.119	.452	.066	.330	-.079	.219
being frustrated reduced self efficacy feeling well cared for by medicos being depressed lifestyle changes; diet, smoking, drinking concern about future social support coping with medical technology	.275	.287	-.002	-.300	.039	.205	.104	.468	.227	.535	.690	1,000	.154	.357	.113	.347	-.101	.310
being frustrated reduced self efficacy feeling well cared for by medicos being depressed lifestyle changes; diet, smoking, drinking concern about future social support coping with medical technology	.263	-.085	-.096	-.235	.252	.240	.175	.125	.080	.095	.119	.154	.1000	.091	.203	.102	.038	.256
being frustrated reduced self efficacy feeling well cared for by medicos being depressed lifestyle changes; diet, smoking, drinking concern about future social support coping with medical technology	.112	.258	-.122	-.041	.275	-.094	-.036	.207	.236	.328	.452	.357	.091	1,000	-.054	.384	.072	.004
being frustrated reduced self efficacy feeling well cared for by medicos being depressed lifestyle changes; diet, smoking, drinking concern about future social support coping with medical technology	.108	-.040	.184	-.213	.067	.107	.218	.147	.018	.127	.066	.113	.203	-.054	1,000	.078	-.061	.112
being frustrated reduced self efficacy feeling well cared for by medicos being depressed lifestyle changes; diet, smoking, drinking concern about future social support coping with medical technology	.136	.354	.091	-.116	.143	.004	-.037	.423	.410	.325	.330	.347	.102	.384	.078	1,000	-.138	.250
being frustrated reduced self efficacy feeling well cared for by medicos being depressed lifestyle changes; diet, smoking, drinking concern about future social support coping with medical technology	.563	.058	-.127	-.049	.143	-.130	-.083	-.017	.026	.093	-.079	-.101	.038	.072	-.061	-.138	1,000	-.009
being frustrated reduced self efficacy feeling well cared for by medicos being depressed lifestyle changes; diet, smoking, drinking concern about future social support coping with medical technology	.182	.182	.026	-.346	.112	.174	.062	.351	.106	.106	.219	.310	.256	.004	.112	.250	1,000	.009

