PSYCHOSOCIAL CORRELATES OF THE SHORT TERM COURSE OF MULTIPLE SCLEROSIS

A thesis presented in partial fulfilment
of the requirements for the degree
of Doctor of Philosophy in Psychology
at Massey University

Sheryl Corinne Zika

1996

ABSTRACT

The present investigation developed and tested a theoretical model, which attempted to depict some of the complex relations among the psychosocial and physical health experiences of multiple sclerosis (MS) patients. The model is comprised of five constructs: psychological well-being, physical health status, stressors, disposition and social support. The pivotal aspect of the model is psychological well-being, through which all other factors exert their influence.

The study consisted of a cross-sectional and a longitudinal phase. Participants in the cross-sectional phase were a convenience sample of 45 people diagnosed with MS. The longitudinal phase involved a subsample of 12 people for an additional six months. In the cross-sectional phase, one structured interview was conducted at the participant's home. The longitudinal participants completed (six) monthly structured interviews and physical examinations (by a physician) at the rehabilitation unit of the local hospital.

Four strategies were used to analyze and interpret the data. Firstly, the cross-sectional data was analyzed using conventional between-subject regressions to examine aggregate relations at a single point in time. Secondly, the longitudinal data was analyzed using within-subject regressions to examine aggregate associations among changes in the variables. Thirdly, the longitudinal data was analyzed to examine intraindividual patterns. Lastly, a qualitative case study approach was used to interpret the factors preceding and following an exacerbation in one participant.

Results of the cross-sectional analysis revealed that disposition and stressors were both related to psychological well-being but, unexpectedly, physical health status and social support had no associations with well-being. Stressors demonstrated an association with physical health status, and disposition was related to social support. The within-subject regressions suggested that disposition and social support moderate how changes in stressors impact on changes in psychological well-being, and how changes in emotional states impact on changes in physical health status. An association was found between

stressors and physical health status. The intraindividual findings revealed that, in general, the variables within each major construct related to one another in line with conceptual expectations. When examining associations between constructs, aggregate findings, for the most part, could not be replicated at the individual level. The case study suggested that changes in stressors and psychological well-being precede and follow a relapse in the disease.

Overall, the findings provided mixed support for the theoretical model. However, the quantitative findings, in combination with contextual information and observational evidence, contributed valuable insights regarding the MS illness process. During relatively stable periods of the disease, in general, psychological functioning does not appear to influence physical functioning, or vice versa. Persons with MS appear to use denial and other defence mechanisms to help them cope with their illness. The appropriateness of the methodological approaches used are discussed, and some of the difficulties in conducting research with MS patients are highlighted. Finally, limitations of the present study are noted and suggestions are made for future research.

ACKNOWLEDGEMENTS

I am grateful to my chief supervisor, Dr John Spicer, for his guidance throughout the various stages of this thesis. His excellent research skills assisted and extended my academic development, and his patience with my learning process was greatly appreciated. I would like to thank my second supervisor, Kerry Chamberlain, who also performed a major role in guiding the present investigation. In particular, his knowledge of the literature and his assistance in clarifying theoretical issues was highly valued. I would like to extend my gratitude to Dr Peter Disler for his medical advise during the planning of the study and his assistance during the data collection phase. He graciously gave of his time to conduct physical examinations and collect medical data.

Appreciation is given to Dr Monica Skinner for her helpful advise on formatting and her assistance with proof reading this document. I would like to thank Kathleen Newman for her excellent illustration of the theoretical model, Julia for her help with formatting graphs, and Ellie for her assistance with proof reading tables.

Thankfulness is extended to the Multiple Sclerosis Society for their assistance in locating participants for this study. I am grateful to the MS field officer, Shelley Smith, for her support and help with transportation during the data collection phase of this project.

My family has been a tremendous support throughout the years of this project. Shari, Danielle and Adam needed to make many sacrifices to allow me time to attend to my work. My husband Bill, through his understanding, support and practical assistance made the completion of this thesis possible. Encouragement from friends was also greatly appreciated.

Finally, I would like to warmly thank the many participants in this study who gave so much of themselves and their time to contribute to this investigation. There could not have been a study without their commitment and co-operation.

TABLE OF CONTENTS

CHAPTER 7: INDIVIDUAL RESPONSE PATTERNS

LIST OF FIGURES

LIST OF TABLES

CHAPTER 1

INTRODUCTION

OVERVIEW

The aim of this study is to examine the relationship of a range of psychosocial factors to physical health factors in people with multiple sclerosis (MS). To accomplish this, an original theoretical model was developed. The model identifies intrapersonal psychological factors and interpersonal social factors that may have a relationship with somatic health changes over the short course of the disease. The psychosocial factors posited to associate with changes in physical health status are: stressors, psychological well-being, disposition and social support. In chapter 3, the development of the model and the criteria for inclusion of constructs and variables are discussed in detail. At this point however, it is important to note that the model does not focus on demonstrating adaptation to MS, nor focus on any specific outcome.

The current investigation was concerned with what a person experiences during the monthly course of their illness. The psychosocial factors that may have been present before the onset of MS, and the possibility that they played a role in making a person more vulnerable to the disease, were therefore not considered. The seven month time frame of the study is relatively short, and hence major changes in physical functioning were not expected. It was assumed, however, that the more subtle processes that take place, psychologically, socially and physically, were also worthy of attention. For most people, lengthy intervals occur between episodes when the disease is actively causing deterioration. Nevertheless, daily functioning and emotional well-being are, for many people, constantly influenced by their illness, and psychosocial factors may continually affect disease activity. In the present investigation, major relapses in MS were not of primary concern, though this may have occurred for some people involved in the study.

The present study is concerned with the experiences of a small group of people with

MS. For a number of reasons, the results from this investigation cannot necessarily be generalised to other MS patients. The people who were involved in this study are a convenience sample and do not comprise a clinically homogeneous group. Further, the decision not to include a control group, and some of the analysis strategies utilised limit the generalisation of results. The measures used were altered from their published form in many cases, to ensure a more pure representation of the construct being assessed, to avoid confounding with other variables in the theoretical model, or for pragmatic reasons. Therefore, the results of this study may not be directly comparable with other studies using the same, but unmodified, measures. However, adopting these approaches has allowed the study to attempt more complete analyses of the MS experience than those usually undertaken.

The aims of the current study required that two equally important but differing paths of analysis be pursued. Firstly, the researcher was concerned with interpreting relations in the theoretical model at the aggregate level using two different analytic approaches. A conventional cross-sectional between-subject approach was adopted to test the construct associations, at one point in time, in a relatively large group of people. A longitudinal within-subject approach, based on a small sub-sample of 12 people, was then utilised to test the associations between constructs as they changed over the seven month period of the study.

Secondly, the researcher was interested in understanding relations in the model at the individual case level. To achieve this, the longitudinal quantitative data was analysed for each of the 12 cases, with emphasis on how variables change singly and jointly over time. In addition, a qualitative case study is presented to show in detail how changes in psychosocial factors relate to changes in disease activity. Neither the aggregate nor individual level approach is deemed to be more important than the other, but rather, they are viewed as complementing one another in providing different parts to a complex puzzle.

This chapter begins with a brief consideration of medical aspects of multiple sclerosis. To understand the relevance of the psychosocial factors examined in the study, some

knowledge about the medical aspects of MS is necessary. However, as the central orientation of this research is psychological, only a brief medical summary will be included. The chapter then discusses the significance of the unpredictable course of MS and presents a succinct historical overview of psychological factors implicated in the disease process. Chapter 2 presents a review of relevant recent literature focusing on psychosocial factors in MS. Chapter 3 focuses on the development of the theoretical model and the selection of constructs and variables for the present study. Chapter 4 discusses the selection of subjects, questionnaire development, measures and strategies for analyses. Chapters 5 to 8 present four different approaches to analyzing and interpreting the data. Chapters 5 and 6 focus on aggregate statistics, in contrast to chapters 7 and 8 which focus on individual cases and are descriptive. Finally, chapter 9 interprets the findings, discusses the theoretical model and the methodological approaches used, and makes recommendations for future research.

MEDICAL ASPECTS OF MULTIPLE SCLEROSIS

Multiple sclerosis is a chronic, often progressive disease of the central nervous system. Neurological impairment occurs as the result of patches of inflammatory demyelination (also referred to as plaques) which are scattered through the white matter of the brain and spinal cord (Willoughby, 1990). The disease is characterised by multiple plaques, hence the name multiple sclerosis. Symptoms are diverse and commonly include complaints of visual disturbances, speech disturbances, weakness or paralysis of limbs, poor coordination, numbness or pin-and-needles, psychological changes and poor bladder and/or bowel control (Lechtenberg, 1988). Although the majority of symptoms are in the physical domain, psychological functioning can also be impaired. Some of the psychological problems that can occur include: cognitive changes, depression, emotional lability, and fatigue (Grant, 1993). Symptoms are often transitory and nonspecific at the onset of the disease and become more specific and pronounced as the disease becomes established (Grant, McDonald, Patterson, & Trimble, 1989).

Diagnosis of MS is difficult, relies partially on observing the course of the disease, and therefore is not usually made for months or even years after the initial symptom(s)

appear (Lectenberg, 1988). Until a firm diagnosis is reached, living with constant uncertainty is often very distressing for the person experiencing symptoms. There are no laboratory tests that can diagnose MS unequivocally, although magnetic resonance imaging scans can be useful in confirming the larger clinical picture (Burks, 1992). Criteria for the diagnosis of MS have changed throughout the years, and an excellent review of this material is presented by Kurtzke (1988).

The course of multiple sclerosis is unpredictable and can not be determined at the time of diagnosis. Burks (1992) describes five courses of MS as: relapsing-remitting, relapsing-remitting followed by chronic-progressive, chronic-progressive, benign and malignant. Most people with MS experience a relapsing-remitting course, and the disease process is characterised by inactive periods interspersed with relapses or exacerbations. However, Burks (1992) asserted that the relapsing-remitting course of MS often changes to a chronic progressive course when a person is in his/her forties or fifties.

The aetiology of multiple sclerosis is unknown, although both environmental and genetic factors are believed to be involved. Generally, evidence suggests that an infectious agent (probably a virus or viruses) acquired during childhood may be implicated. However, the immune system, particularly the T-cell receptors, appears to play a major role in the demyelination process (Burks, 1992). Recent theories propose that MS is an autoimmune disease initiated within the central nervous system, although no single antigen has been identified (Calder, Owen, Watson, Feldmann, & Davison, 1989). The acquisition of MS is believed to take place around puberty, although the onset of the symptoms does not occur for an average of 12 years (Lechtenberg, 1988). Characteristics that describe persons most at risk for developing MS are described by Burks (1992): Caucasians more than other racial groups, females more than males, diagnosis usually between 20 and 50 years, lived in temperate climates before the age of fifteen, higher socio-economic groups, and a family history of MS.

The aspect of MS epidemiology that is most relevant to the present study is that New Zealand has a relatively high incidence of this disease. Geographically, there is an

increase in prevalence rates from north to south, attributed to higher latitudes (Skegg, Corwin, Craven, Malloch, & Pollock, 1987). The prevalence of MS in the Waikato (North Island) is 23.6 per 100, 000, in contrast to Otago and Southland (South Island) which has a prevalence of 68.5 per 100,000 (Skegg et al., 1987). In both regions, the prevalence rate is higher for females than males; 2.7:1 in the north and 3.0:1 in the south. The Manawatu region, where the present study was conducted, lies between Waikato and Southland, and has a intermediate prevalence rate of 38.7 per 100,000, with a female/male ratio of 2.2:1 (Disler, Gregory, Firth, & Disler, 1993).

There is no known cure for multiple sclerosis, and treatment methods, until recent years, have been varied, experimental, and not particularly effective. The contemporary medical approach focuses mainly on medications, for either symptomatic treatments or immunomodulating therapies (Burks, 1992; Lechtenberg, 1988).

To conclude, multiple sclerosis is a poorly understood disease. The aetiology of the illness is unknown, diagnosis is difficult, the course of the disease is unpredictable, treatment methods can, at best, control the symptoms and slow down the course of the illness, and there is no known cure. Multiple sclerosis is not usually a fatal disease. However, it is, in most cases, chronic and progressive, and produces a variety of distressing symptoms, often eventuating in major deterioration and disability.

THE COURSE OF MS: IMPLICATIONS FOR RESEARCH

One of the most striking aspects of MS, mentioned earlier, is the unpredictability of the course of the illness for any given person. At one extreme, a person who has a benign form of the disease may experience a single exacerbation of MS, followed by a full recovery and no long term disability. At the other extreme, an individual with a malignant course may have numerous relapses with no recovery, and die within a few months of the onset of the disease. As mentioned previously, at the time of diagnosis, and indeed sometimes for many years, there is no way of foreseeing how the illness will develop.

Medical explanations cannot account for the differences in the way in which the course of the disease develops for any given individual. There are a few guidelines that indicate a more favourable prognosis, but they do not hold true for all people (Burks, 1992). Even more confusing, symptoms and signs are not necessarily a true indication of disease activity (Poser, 1980). An exacerbation may either represent the occurrence of a new plaque, or a manifestation of an old plaque from a physiological alteration (Peyser & Poser, 1986).

Some physical factors are known to bring on symptoms of MS, including: heat, changes in calcium concentration levels, dehydration, and infection (Peyser & Poser, 1986). In addition, for women, there appears to be a hormonal link with disease activity. This is evident during pregnancy, when exacerbation rates decrease, but increase during the postpartum period (Burks, 1992). However, these factors account for only a small amount of the variation found in the course of the disease.

The paucity of information about determinants of the course of MS, and a deficiency of solid medical explanations, has invited consideration of additional factors that may affect the illness process. Psychologic factors, although less understood than physical factors, have been proposed to influence the course of multiple sclerosis (Grant, Brown, et al., 1989; Mei-Tal, Meyerowitz, & Engel, 1970; Philippopoulos, Wittkower, & Cousineau, 1958; Poser, 1980, 1981).

The uncertainties of the disease and the inability to control its course are features of MS that are likely to have consequences for psychological functioning. Research that considers the interplay between psychosocial and disease-related factors may provide ways to better understand the experiences and needs of MS patients.

PSYCHOLOGICAL ASPECTS OF MS: THE EARLY LITERATURE

Interest in MS from a psychological perspective is certainly not new. To fully understand the contribution of recent studies, it is valuable to consider the precursors of current trends in thinking. Although a comprehensive review of the classic studies

will not be presented, the general themes of the early literature will be discussed.

Some of the first assertions about the psychological features associated with MS are attributed to Charcot (1877, cited in Surridge, 1969). From his observations, Charcot concluded that patients with MS displayed intellectual deficits, inappropriate affect, and psychic disorders. A number of accounts of MS, in the late nineteenth and early twentieth centuries, concentrated on abnormal personality features, such as Vulpian's view of "morbid optimism" and Hoffman's observation of euphoria (Surridge, 1969). Pioneering studies on psychiatric aspects of MS were fraught with discrepancies and contradictions, partly because of the difficulties in diagnosing MS accurately (Surridge, 1969).

Around the 1940s, there was considerable interest in psychosomatic disorders, and researchers started a more systematic study of the psychological and psychiatric aspects of MS (Philippopoulos et al., 1958). In many of these studies, Freudian and similar analytical theories, which were popular at the time, appeared to influence clinical interpretations. In a classic investigation by Langworthy (1948), based on five intensive case studies, female patients with MS were described as emotionally immature, caught up in neurotic relationships with a parent, and having sexual disorders ranging from promiscuity to frigidity. Langworthy was one of the first researchers to consider the impact of emotional turmoil on disease activity.

In the next three decades researchers continued to examine psychological aspects of MS. The most prominent issues concerned the emotional states of people with MS and the role of emotional stress in the onset and progress of the disease. Mei-Tal et al. (1970), as a prelude to their study, reviewed a number of studies from the 1950s such as the following. Brickner reported, based on the records of 50 patients, that emotional stress would sometimes precede attacks of MS. Grinker studied 26 people with MS. He concluded that major changes in a life situation, which should have activated intense resentment or anger, or which required excessive mental or muscular strain, were often a precipitating factor of symptoms. Pratt examined the role of emotional disturbance on the onset of MS and relapses in 100 patients and 100 control patients. Contrary to

the findings of previous researchers, he concluded, on statistical grounds, that the onset or relapse of MS could not be attributed to emotional stress. However, he conceded that there were individual cases to support a relation between emotional stress and the onset or relapse of the disease.

Philippopoulos et al. (1958), after noting the contradictory findings of prior studies, investigated several aspects of MS including the role of emotional disturbance in the onset and course of MS. They reported that in 35 out of 40 patients, the onset of MS was preceded by traumatic experiences. The nature of the emotional stress was usually chronic rather than acute. Further, Philippopoulos et al. suggested that relapses in MS are often elicited by "worry over financial matters, unhappy home life, increased responsibility, either alone or in combination with such other factors as fatigue, overexertion, overwork, accidents, injuries, and childbirth" (p. 470).

In a review of the literature from 1950 through 1961 on the psychosocial aspects of MS, Cohen (1962) makes some interesting, albeit controversial, observations. He asserted that relatively few publications are available, suggesting this may reflect psychiatrists' and psychologists' limited experience in dealing with personality aspects of MS. He further argued that the studies undertaken in that era are not comparable with one another and generally lack scientific rigor. Cohen, after reviewing all the research findings, concluded that there is no distinctive MS personality, however, particular personality characteristics may be present. These include high dependency needs, depression, anxiety, preoccupation with self, and insecurity. Cohen also concluded that "some support has been given to the position that emotional factors and tensions can set off exacerbations of physical symptoms or induce remissions" (p. 20).

Antonovsky et al. (1968), as part of a larger study on aetiologic factors in MS, studied the role of emotional trauma in the onset of MS. Nine open-ended questions, referring to emotional trauma, were answered by 221 MS patients and 442 random control subjects. The findings showed that patients and controls differed significantly on only one item, suggesting that emotional trauma was not associated with the onset of MS. The study also failed to find evidence that people with MS were more likely to respond

passively to hostile acts, than control subjects.

Surridge (1969) investigated the psychiatric states of 108 patients with MS. He reported that nearly two-thirds of the patients demonstrated intellectual deterioration, varying from mild to profound. Surridge found a quarter of his patients to be depressed, and a quarter of his patients to be euphoric, a third of his patients had experienced personality changes, and 10 percent showed exaggeration of emotional expression. He asserted that all of these states are directly attributed to damage in the central nervous system.

Mei-Tal et al. (1970) studied the role of meaningful life events on the onset and course of multiple sclerosis. The subjects were 32 patients from the United States and Israel. The findings showed that 28 of the 32 patients experienced psychologically stressful experiences directly prior to the onset of MS. In many cases stressful experiences were also involved in exacerbations of the illness. Mei-Tal et al. asserted that the stressful experiences are responded to by feelings of helplessness and giving up, which underlies an inability to cope. Personal circumstances varied, but often focused on threat to life, recent loss, removal of body parts or change in body function, and conflict in the family.

To summarise, the earliest research on psychological aspects of MS was based on observations of patients and interpretations of case studies. The studies were mainly concerned with describing neurotic personality features and mental deficits. From around the 1920s interpretations were often strongly psychoanalytical in nature. In later years, the research focus broadened to include inquiry into emotional disturbances that may precede the onset of MS, or precipitate relapses. In general, these studies demonstrated more empirical rigor, by including control groups and/or psychological measures. However, descriptions of emotional states and stressors were rather ambiguous. Terminology such as emotional disturbance, emotional conflicts, emotional shock, emotional stress, and emotional trauma were used almost interchangeably, without clear definition.

However, in spite of these limitations, early research made a substantial contribution by providing important theoretical foundations for later investigations. Early findings suggested that multiple sclerosis could not be fully understood from a medical perspective, and that psychosocial factors warranted some consideration. In particular, justification was established for examining the role of emotional disturbance and stress on disease activity.

The more recent research in this field, from the past two decades or so, will be reviewed in chapter two. Strong interest in the relation between psychosocial factors and chronic illness is evident from the abundance of studies in the 1980s and 1990s, and extends over a range of diseases, including multiple sclerosis. In more recent years, the emergence of well defined stress theories have impacted strongly on health psychology research, including studies focusing on psychosocial factors in multiple sclerosis. The emphasis on which types of psychosocial factors are worthy of investigation continues to change and evolve, and this trend will be explored in the following chapter.

CHAPTER 2

PSYCHOSOCIAL ASPECTS OF MULTIPLE SCLEROSIS

In recent decades the role of psychosocial factors in multiple sclerosis has gained considerable attention. In this chapter, literature most relevant to the present study was selected for review. Therefore, studies that have investigated the psychosocial factors depicted in the theoretical model of the present study are included. The constructs of interest are: stressors, psychological well-being, social support and dispositional characteristics. A number of studies are reviewed that have considered the relation of life events or chronic minor stressors to the MS illness process. The review also includes descriptive studies about the prevalence of depression and other emotional disturbances among people with MS, and studies that have focused on the association between emotional states and disease activity. Finally, studies examining the role of social support and dispositional characteristics to health status and adaptation in MS are reviewed. The present study focuses in the main on the interplay of psychosocial and physical health factors over the short course of MS. Hence process orientated studies were particularly appropriate for inclusion in this review.

STRESS

Of all the psychosocial factors that have been implicated in the course of MS, stress has probably received the most notice. Support for the role of stress in the MS illness process is provided from both clinical and empirical findings. Before reviewing the literature, there are two general issues concerning stress that need to be addressed. Firstly, depending on the theoretical orientation accepted, stress may be viewed as a precipitant or a consequence of MS, although these positions are not mutually exclusive. Poser (1980), citing clinical observations, argued the need to recognise stress as a precipitant of relapses in MS. He commented :

> Careful reconstruction of events preceding exacerbations frequently uncovers episodes or sustained periods of psychologic stress, often quite subtle, days or

> weeks preceding the appearance of symptoms. The history of many MS patients reveals instances of severe illness or death of a close family member, marital discord, employment changes, financial distress, or academic pressures during the days or weeks preceding exacerbations. (p. 472)

Poser's view implies that stress precedes or triggers the exacerbation, however, it is equally valid to consider stress as a direct result of the disease or as a reaction to the illness (LaRocca, 1984). LaRocca pointed out that MS strikes people during peak years of career and family development, and therefore the repercussions that occur in physical, psychological, social and financial domains can be extremely stressful. He proposed that the most accurate model of stress would represent stress as both an antecedent and a consequence of illness.

Secondly, the way in which stress is defined has important implications when interpreting research findings. In recent research, stress has usually been defined as stress stimuli (stressors), or specifically, environmental events. These events are viewed as major changes or as daily hassles (Lazarus & Folkman, 1984). It has already been mentioned that in early studies on MS, stress was not well defined, and the term was often used to describe any type of emotional disturbance. In later studies stress has been, in most cases, defined more distinctly, leading to advances in the field.

The early studies on the influence of stress on the course of MS were described in chapter 1. In addition, a number of recent empirical investigations have been published in this area.

Several studies have focussed on the association of stressful life events with exacerbation of the disease. Rabins et al. (1986) assessed stressful life events in 87 people with MS over a one year period. Each month participants completed the Holmes-Rahe Schedule of Recent Experiences (SRE) to provide serial measurements of stressful life events. Twenty-three people experienced exacerbations during the study, and of those, 20 had completed more than one SRE prior to his/her relapse. The mean SRE score for an individual was compared with his/her SRE score just prior to the exacerbation. Findings showed that in only three cases were the SRE scores more than 1 *SD* above

the person's mean score, and in two cases the scores were more than 1 *SD* below the person's mean score. Rabins et al. concluded that the data did not support an association between stress and illness activity, though people tend to believe that stress is related to their illness.

Franklin, Nelson, Heaton, Burks, and Thompson (1988) investigated the relation between stressful life events and acute exacerbations in MS. The prospective study involved 55 MS patients, who completed the Psychiatric Epidemiology Research Interview (PERI-M) at 4 month intervals, until an acute exacerbation occurred for 20 people (mean follow-up period 20 months). The PERI-M was used to scale stressful life events according to their contextual importance. The 20 exacerbating cases did not report a greater number of stressful life events than the 35 control cases. However, relative risk analysis revealed that people who experienced more intense events were 3.7 times more likely to relapse than subjects who did not report such extreme events. Franklin et al. asserted that the quality, rather than the number of stressful life events put people at risk for exacerbation. This study had many strengths including a prospective and longitudinal design, and a well defined stress measure that assessed the quality of stressful experiences. It did not however (as acknowledged by the researchers), measure potential moderator variables, which may have provided a more complete representation of the exacerbation experience.

In a study focused on a similar theme, Grant, Brown, et al. (1989) examined the relation between difficult life events and onset of major symptoms (either initial or exacerbations) in MS. Thirty-nine patients with early MS (median 2 years) and 40 matched healthy controls, completed the Life Events and Difficulties Schedule in a semi-structured interview, to provide assessments of recent life events and ongoing life happenings. Stressful events were rated for degree and duration of threat, as well as focus (self versus other), and ongoing life happenings were rated for level of severity. Depending on the ratings, events and ongoing happenings were categorised as either marked adversity, severely threatening events, or marked difficulties. The findings indicated that MS patients had a significantly higher incidence of marked adversity and severely threatening events, as compared with controls. During the six month period

prior to onset of major MS symptoms, 77% of the MS group reported marked adversity as compared to 35% of the control group. Sixty-two percent of the MS group, in contrast to 15% of controls reported a severely threatening event. Although the results indicate that severe stressful life circumstances are more common for people with MS (prior to the onset of major symptoms) than for healthy people, the retrospective design of the study has limitations. Some people in the study were asked to remember events that occurred two to three years earlier, and may have unintentionally supplied reasons for their illness, introducing recall bias. Also, a causal relationship between stress and symptom onset can not be confirmed from this data.

In Israel, Nisipeanu and Korczyn (1993) prospectively studied the relation between a major psychological stressor and exacerbation in MS. Thirty-two MS patients living in Tel Aviv were evaluated over a two year period (1989 to 1990) for disease activity. Subsequently they were assessed during the Persian Gulf War of 1991, during which 18 SCUD missile attacks and five false alarms occurred. Patients were contacted and interviewed frequently during the period of war and for the following two months. Findings indicated that only three people had relapses during that period, significantly less than the number of relapses reported in the previous two years. Nisipeanu and Korczyn concluded that severe stressors do not increase the risk of exacerbation in MS, and conversely, through their impact on the immune system, may provide a time limited protective function. The study has advantages due to the prospective design, however, there were drawbacks because of its narrow conceptual focus. Neither individual perceptions of the crisis, nor moderator variables were considered. For example, social support could be a very important influence during a shared catastrophic event.

In a study focusing on the role of stress in the aetiology of MS, Warren, Greenhill, and Warren (1982) examined the relation of stressful life events to the onset of the disease. One hundred MS patients and 100 neurological and rheumatology control patients were interviewed to obtain details about stressful life events that occurred in the two years prior to illness onset. An artificial onset age was established for the control subjects based on the onset age of their MS matched control. Stressful life events were placed into one of nine categories, derived from the work of Holmes and Rahe (1967). The

MS group reported more stressful life events in each of the nine categories relative to the controls (although tests of significance were not performed). Significantly more MS patients than controls reported that the events they had described placed them under more stress than usual during the two years prior to the onset of MS. Significantly more MS patients than controls reported three or more stressful events. MS patients and controls were also compared on subjective early childhood experiences, self-reported emotional style (tense versus easy going) prior to illness onset, and frequency of seeking professional assistance for an emotional problem. However, there were no significant differences between the groups on any of these characteristics. The findings suggest that people with MS are exposed to higher levels of stressful life events prior to the onset of the disease, relative to other patient groups. The study was among the first to use a case-control method and a well defined construct of stress, but nevertheless had some drawbacks. As noted by Warren et al. (1982), the frequency of stressful events were measured without assessing the magnitude of the stressors. It is possible that the intensity of the stressors, rather than the number of stressors, place people at risk for developing MS. Further, the study is retrospective in design and required participants to recall stressful life events that occurred years prior. Finally, the artificial onset age used for the control subjects could have made it more difficult to recall stressors, as the stressors were appraised in relation to age, rather than prior to a specific event as was the case for the MS group.

Although most studies have focused on major stressful events, minor chronic stressors, or hassles have also been considered. Warren, Warren, and Cockerill (1991) compared MS patients in remission with those in exacerbation on stressor levels over the previous three month period. Subjects in remission and exacerbation were matched on gender and age, resulting in 95 matched pairs. The Hassles Scale was used to assess minor frustrating stressors. No difference was found between exacerbation and remission groups on frequency of daily hassles, however, intensity of hassles was greater for the exacerbation group. Warren et al. (1991) concluded that the perceived impact of a stressor may be more important than the number of stressors experienced. This study has advantages in including a large sample, involving a matched control group of people in remission, and relying on recall of stressors after a relatively short period. However,

it is retrospective in design and therefore, can not establish a causal relationship.

Considered together, the studies provide mixed support for the relation between stress and disease activity in MS, although the weight of evidence indicates that there is an association. With the exception of findings from Rabin et al. (1986) and Nisipeanu and Korczyn (1993), the results suggest that intense stress is associated with disease onset and/or exacerbation in MS. However, the two studies that do not support this relation are based on prospective data and provide convincing counter arguments. Findings indicate that the quality of stress, whether conceptualised as major stressful events or minor hassles, is more important than the quantity of stress in influencing disease activity (Franklin et al., 1988; Warren et al., 1991).

PSYCHOLOGICAL WELL-BEING

A number of recent studies have considered the emotional impact that multiple sclerosis has on individuals, and some have considered whether emotional states influence the disease process. Many of these investigations focus on depression, in contrast to the emphasis on euphoria found in earlier studies. To a lesser extent, other aspects of well-being have also been investigated. However, the accent has been on negative emotional states rather than positive states.

Occasionally, people with MS develop severe intellectual deterioration (Young, Saunders, & Ponsford, 1976) or serious psychopathology, including pathological laughing and weeping, mania, bipolar disorder, and psychosis (Minden & Schiffer, 1990). These psychiatric conditions are outside the scope of the present study and will not be discussed in detail, although they may constitute minor elements of studies that will be reviewed.

Before discussing specific studies on the emotional impact of MS, there are some issues that deserve reflection. As was the case with stress, researchers are not in agreement about the causal relation between emotional states and MS. For example, most studies conceptualise depression as a emotional reaction to living with the illness, in contrast

to other studies that view depression as contributing to the onset or progression of MS (Devins & Seland, 1987). A further persistent concern is whether depression and other affect states are a direct result of the physical disease process, specifically demyelination of the limbic structures, or are psychological reactions to the illness (Minden & Schiffer, 1993).

Another point worth noting is whether, as a result of methodological or conceptual bias, studies overestimate the degree of emotional distress experienced by people with MS (Eklund & MacDonald, 1991). It is claimed that the inclusion of certain measures for assessing emotional disorders can sometimes elicit misleading results. For example, two measures commonly used, the Minnesota Multiphasic Personality Inventory (MMPI) and the General Health Questionnaire (GHQ), include a number of somatic symptoms of distress. It has been argued that physiological symptoms can be interpreted as psychopathology, inflating the severity of emotional distress (Devins & Seland, 1987; Eklund & MacDonald, 1991). It has also been asserted that researchers' preexisting bias of perceiving people with MS to have severe psychopathology, may influence the interpretation of data (Eklund & MacDonald, 1991). Although these arguments are credible and should be taken into consideration, they do not present a serious problem. Recent studies have used a variety of standardised well-being measures, other than the MMPI or GHQ. Further, it is unlikely that research in any field can be totally free from conceptual bias, in one direction or another.

Returning to the role of depression in MS, many studies have focused on this association. Several studies have concentrated on establishing whether there is a higher prevalence of depression in MS patient groups than in comparison groups. In a recent meta-analysis (Schubert & Foliart, 1993) of five controlled studies on depression, MS patients were found to have higher rates of depression than comparison groups. This pattern emerged even when MS patients were compared to other chronic illness groups. The effect sizes ranged from 0.19 to 0.84, and the summary statistic $z(t)$ was 4.68, which is highly significant.

Two studies included in the meta-analysis and illustrative of the research in this area,

will be discussed further. Whitlock and Siskind (1980) compared 30 MS patients with 30 chronic neurological disease patients on experiences of depression. Participants were interviewed by a psychologist and completed the Beck Depressive Mood Inventory. The MS patients and control patients were matched for sex, age and degree of disability. The MS patients were found to be significantly more depressed than the control patients. Further, the MS patients, relative to the controls, reported significantly more depressive episodes prior to the onset of their illness. Depression was not related to length of illness, and current level of disability was not related to prior history of depression. This study was among the first to use a control group, but had drawbacks because of the relatively small sample size and the retrospective design.

Minden, Orav, and Reich (1987) studied past and current levels of depression in 50 MS patients. The participants were interviewed by a psychiatrist and completed several measures including the Schedule for Affective Disorders and Schizophrenia, and the Beck Depression Inventory. Diagnosis of psychiatric disorders were based on last week, last year, and lifetime criteria, with attention to when the disorder developed relative to the onset of MS symptoms. MS patients were then compared with four community samples on prevalence of disorders. MS patients demonstrated a significantly higher rate of lifetime, current and 1-year affective disorders than the comparison groups. Further, MS patients were found to be more depressed than other medically ill patients reported in the literature. Thirty-four percent of MS patients met the criteria for major depression during the preceding year period. In total, 54% of MS patients reported at least one major episode of depression since the onset of their illness. The severity of current depression was unrelated to severity or type of disability, duration of symptoms, fatigue, type of MS, clinical status, socioeconomic status, age or gender. Minden et al. concluded that MS directly contributes to the occurrence of depression, although their data could not explain the aetiology of depression. They suggested that depression results from a complex interaction of pathophysiology, stress, and other individual factors.

In a study not included in the Schubert and Foliart (1993) meta-analysis, Hickey and Greene (1989) compared 45 community based MS patients with other populations

reported in the literature, in terms of depression and hopelessness levels. They found the MS group to have significantly higher levels of depression than a sample of the general population, and males, but not females, to be significantly more depressed than psychiatric hospital inpatients. Further, they found the MS group to be significantly more hopeless than a random community sample, and more hopeless than other groups of physically ill people. In contrast, the MS group did not show greater hopelessness when compared with a chronic pain group or with psychiatric patients. The MS group was significantly less hopeless when compared with a group of suicide attempters who had an intent to die, but was significantly more hopeless when compared with a group of suicide attempters with no intent to die.

However, not every study has reached the same conclusion in regard to depression. As part of a larger study, Eklund and MacDonald (1991) examined emotional functioning, including depression, among 125 people with MS, and compared the scores with a normative population. Participants completed a mailed questionnaire with a number of measures including the Anger-Fear-Depression Personality Questionnaire (AFD) and the Thoughts about Suicide Scale. Subject's scores on the eight subscales of the AFD were compared with normative data. People with MS scored significantly higher on muscle tension, physiological arousal, and hostility avoidance than the normative group. However, the MS group scored significantly lower on defensiveness and depression. Although the majority of participants were not suicidal, 12.6% reported a moderate to strong wish to die. Eklund and MacDanald concluded from these findings and others not discussed here, that people with MS successfully adapt to their disease. It is questionable whether the findings on suicidal ideation support their view, as they provide at least some indication of distress among a sizeable minority of the group. Further, the study used cross-sectional descriptive data exclusively, but comments about adaptation, which implies change over time.

Harper, Harper, Chambers, Cino, and Singer (1986) compared 301 MS patients with general populations on psychological well-being and quality of life. MS patients were assessed using a range of measures, including the Rand Social Health Index, Rand Mental Health Index (MHI), and the Andrews-Withey Quality of Life Index. The MS

group was found to have significantly worse health than the comparison groups in the domains of physical health, social health, emotional health and perceived quality of life. Within the MS group, severity of disease was associated with deterioration in both social health and quality of life, but was unrelated to emotional health. Harper et al. asserted that "emotional problems occur independently of the severity or stage or progression of the disease" (p. 309). However, they acknowledged that due to the cross-sectional design of the study, disease severity was considered without regard to change in levels across time. They proposed that changes in disease status may be more important to emotional health than disease activity per se. This is an interesting observation, but unfortunately cannot be confirmed from the available data.

In a descriptive study, McLellan et al. (1989) examined the occurrence of depression and anxiety in 305 people with MS. Depression and anxiety were assessed with the Hospital Anxiety and Depression Scale. Seven percent of the participants were found to be depressed, 9% border-line depressed, 16% anxious, and 20% border-line anxious. The rate of depression in men was four times as great as it was in women. For men depression was related to disability, but not to illness duration or age. Whereas, for women, depression was related to disability, illness duration and age. Anxiety was equally frequent for men and women, and was not related to severity of disability or duration of illness, but was associated with younger age. As a survey which included a large sample, and used a depression measure that is free from somatic content, it provided some useful information, albeit with the limitations of a descriptive study.

A number of studies have focused on the relation of emotional states to illness activity. Dalos, Rabins, Brooks, and O'Donnell (1983) studied emotional disturbance in 64 MS patients and 64 spinal cord injured (SCI) control patients. Participants were followed on a monthly basis for one year. Twelve of the 64 MS patients experienced exacerbation or progressive illness during the study period. Using the GHQ as self-completion questionnaires, four aspects of distress (somatic complaints, anxiety, social dysfunction, and depression) were assessed. MS patients in remission had a significantly lower mean GHQ score than MS patients in exacerbation or with progressive illness. Further, the rate of emotional disturbance was 90% in exacerbating

or progressive patients, as compared to 39% in remitting patients and 12% in SCI control patients. MS patients in exacerbation were significantly more depressed than both MS patients in remission and SCI controls. A detailed analysis of 9 MS patients who experienced both remissions and exacerbations in the study period, revealed that for 8 of these, somatic dysfunction, anxiety, and social dysfunction were all elevated during exacerbations. Five out of 9 patients also showed increases in depression scores during exacerbation. Dalos et al. asserted that potentially severe emotional disturbance is related to increasing disease activity. The prospective longitudinal design of the study was useful in allowing an examination of the illness process over time.

In another more recent study concerned with affect and MS activity, Warren et al., (1991) compared emotional disturbance levels in 95 pairs of MS patients, each in remission or exacerbation. Emotional disturbance was assessed with the GHQ, though sub-scales scores were not reported. A score of 5 or above on the GHQ was used to discriminate between normal and emotionally disturbed individuals. For people in exacerbation 56.8% scored 5 or above, as compared to 28.4% of people in remission. The findings supported the relation between emotional disturbance and relapse. The study has advantages in comparing people in remission with those in exacerbation. However, because of the cross-sectional design it is not possible to determine whether emotional disturbance is a cause or consequence of exacerbation. Further, the use of the total GHQ score, without consideration of the sub-scales, limits the information that can be gained from the data.

As part of an extensive longitudinal study, Rabins et al. (1986) prospectively investigated emotional disturbance in people with MS over a one year period. Eighty-seven MS patients, and a control group of 16 spinal cord patients, were given neurological examinations and assessed monthly on psychological and physical status variables. Emotional disturbance was measured using the GHQ, and global scores as well as specific scores for somatic distress, anxiety, social dysfunction, and depression were obtained. Forty-seven percent of people had a mean GHQ score at or above 5, indicating a chronic level of emotional disturbance. The MS patients were significantly more emotionally disturbed than the spinal cord controls. In MS patients, emotional

disturbance (total GHQ score) was not related to age, marital status, income, presence of children, length of illness, or neurological impairment. However, anxiety and depression were both significantly related to neurological impairment. Emotional lability over the study period was significantly associated with general emotional disturbance, as well as with somatic complaints, social dysfunction, anxiety and depression. Rabins et al. argued that many MS patients suffer from chronic emotional disorder. They view this disturbance both as a reaction to the illness and as a manifestation of brain lesions, and indicate that their data supports both positions. This study benefits from the prospective, longitudinal design. However, as the researchers noted, the inclusion of a measure to assess specific symptoms, in addition to the impairment measures, would have improved the study methodology. Further, although the data was available, the relation between emotional disturbance and exacerbation of the illness was not reported.

The relation between illness activity and mood in MS was investigated by Gatten and Brookings (1993) who followed the affect changes of twelve female MS patients twice weekly for eight weeks. Subjects completed an affect check-list that contained 40 adjectives which described eight affect states, and rated their overall health from poor to excellent. The affect scores for all episodes (total 192) were factor analysed using a chain P-technique and three factors were identified: positive affect, negative affect, and fatigue. The factors each correlated moderately (PA r = .62, NA r = -.54, F r = -.61) with self-rated physical health. Gatten and Brookings concluded that, for people with MS, disease activity is a major determinant of emotional distress. Although this study has an advantage in using a serial measurement of affect, it is limited by exclusively assessing physical health at a global level. Measurement of MS symptoms would have improved the methodology of the study.

A few studies have focussed on factors that impact on well-being outcomes in people with MS. As part of a more comprehensive study on stress and attitudes, Counte, Bieliauskas, and Pavlou (1983) investigated the relative contribution of trait anxiety, hospitalisations (for MS and in total), age, life stress, knowledge of MS, years of MS, and social class on personal life satisfaction. The Life Satisfaction Index was used to

assess personal life satisfaction in 97 MS outpatients. Stepwise multiple regression analysis showed that trait anxiety, total hospitalisations, age and life stress each impacted significantly on life satisfaction, explaining 45% of the variance. Higher life satisfaction was found among people who were less anxious, younger, reported less stressors, and had fewer hospitalisations. The study made a contribution by showing the relative influence of factors on life satisfaction at one point in time.

Along similar lines, Zeldow and Pavlou (1984) examined the relative contribution of physical health status, life stress, duration of illness and demographic variables on well-being. Well-being was assessed in 81 MS patients using a factor score derived from the California Psychological Inventory, regarded as a measure of personal efficiency and psychological well-being. Stepwise multiple regression analysis revealed that life stress, marital status, and physical health status each impacted significantly on well-being, explaining 30% of the variance. Well-being was associated with fewer stressful events, fewer physical limitations, and being married. The study offered information about the relative contributions of factors to well-being at a single point in time.

As part of a comprehensive study on adaptation to MS, Perry (1992) examined the influence of hassles, uplifts and coping strategies on life satisfaction, satisfaction with health, and self-esteem. The participants were 20 men and 20 women with MS, located through the Belfast MS Society. Half of the people lived in the community and the other half resided in institutions. Subjects took part in a semi-structured interview and completed a range of measures, including Cantril's ladder to assess life satisfaction and satisfaction with health, and the Rosenberg Self-esteem Scale. Fifty percent of people reported being satisfied with their life at the present time, and 35% reported being satisfied with their health. Most people experienced moderate levels of self-esteem. To examine the relative impact of uplifts, hassles and coping on well-being outcomes, each variable was regressed step-wise onto life satisfaction, self-rated health, and self-esteem, in turn. Uplifts and hassles both impacted on life satisfaction and self-esteem, but failed to predict self-rated health. Higher levels of uplifts and lower levels of hassles were associated with better life satisfaction and more positive self-esteem. Avoidance coping impacted on satisfaction with health. Lower levels of avoidance coping were related to

greater satisfaction with health. The study is commendable for including positive well-being outcomes in a research area that has been almost exclusively concerned with negative outcomes. Self-esteem has been used as a measure of adaptation, although it is arguable whether it should be regarded instead as a dispositional factor that influences adaptation.

In an attempt to better understand the diversity of psychological response to MS, researchers have provided tentative psychological typologies of people with MS. Although these studies do not specifically focus on psychological well-being, they are included to illustrate the differences in people's psychological profiles. Two studies that have used cluster analysis to identify specific profiles will be discussed.

In an investigation by Peyser, Edwards and Poser (1980) 55 MS patients participated in neurologic examinations, completed psychological measures and provided demographic information. The MMPI was used to obtain scores on ten clinical scales of psychological functioning. All MMPI mean clinical scores were found to be within the normal range. A cluster analysis was performed on the ten subscales together with demographic characteristics, and disease related variables. A six cluster solution was accepted, each representing a different psychological profile. Cluster 1 consisted of people who had the diseases for the longest time, were cognitively impaired, and tended to have extreme psychological difficulties. Cluster 2 were young people who had the disease for a short time, were cognitively intact, and exhibited psychological denial. People in cluster 3 had a moderate degree of physical impairment, were cognitively intact, and demonstrated evidence of depression, anxiety and somatic concerns. Cluster 4 individuals showed slight physical impairment, a high degree of cognitive impairment, and normal psychological adjustment. People in cluster 5 demonstrated slight physical impairment, were cognitively intact, and displayed a hysterical personality style. Cluster 6 was of men only, who had the disease a short time, and showed evidence of acute psychological distress. The findings confirm the diversity of psychological functioning among people with MS, and the cluster details are informative. However, they are limited because the variables that are included in the analysis determine the scope of the outcome, and the findings cannot be generalised to other people with MS.

Zeldow and Pavlou (1988) attempted to identify distinct types of psychological functioning among 81 MS patients. Four factor scores derived from the 18 subscales of the California Psychological Inventory were included in a cluster analysis, producing types W, X, Y and Z. Type W people (45% of the sample) were mature, poised, self-assured, self-reliant, intelligent, and open-minded. People of Type X (22% of the sample) were concerned with creating a favourable impression, and appeared to deny worries or difficulties. They lacked social skills, self-assurance, and intellectual drive. Type Y people (12% of the sample) showed poise and self-assurance, however, they appeared very unhappy and preoccupied with their illness. Finally, Type Z people (21% of the sample) were outgoing, overbearing, unhappy, self-centred, and inflexible in their thinking. The strengths and limitations discussed in relation to the Peyser et al. (1980) findings are also applicable here.

Overall, the studies in this section provide evidence to suggest that the psychological well-being of people with MS is at risk, particularly when the illness is active. Most findings strongly suggest that people with MS are more likely to suffer from depression and other emotional disturbances, than other comparison groups (Minden et al., 1987; Schubert & Foliart, 1993; Whitlock & Siskind, 1980; Rabins et al., 1986) although, this assumption is disputed by Ekland and MacDonald (1991). When considering well-being more generally, people with MS, as compared to general populations, demonstrate worse emotional health, perceived quality of life, and social health. In general, the results of several studies provide evidence for a relationship between psychological distress and illness activity (Dalos et al., 1983; Gatten & Brookings, 1993; Warren et al., 1991). The findings suggest that emotional disturbance increases during exacerbations, and subsides during remission, although a causal association has not been established. Stress has been found to be associated with worse well-being (Perry, 1992; Zeldow & Pavlou, 1984), and conversely, uplifts have been linked with better well-being (Perry, 1992). Lastly, interpretations of psychological profiles suggest that people with MS experience diverse psychological responses to their illness (Peyser et al., 1980; Zeldow & Pavlou, 1988).

SOCIAL SUPPORT

A large number of publications have resulted from studies on the role of social support in health and illness in the last decade (Schwarzer & Leppin, 1989). However, relatively few studies have examined the function of social support in the MS illness process. Most of these studies view social support as a factor that may influence a person's ability to adjust to MS. In chronic illness models, social support has often been regarded as coping assistance that buffers the impact of stress (Waltz & Badura, 1990). However, the studies reviewed here assume social support has a direct relation to illness adjustment. The last study presented examines the reverse influence of physical health status on social support received. It is notable that the type of social support assessed (and measurement instrument used) varies in each study.

Maybury and Brewin (1984) examined a number of factors thought to influence adjustment to MS, including social support, in 36 MS patients. Social support was assessed using a scale of normalisation/disassociation, based on four criteria: whether the patient had moved house since diagnosis, social contact with able-bodied people (excluding immediate family), social contact with other disabled persons, and whether they were members of the MS Society. Contact with able-bodied people was found to relate to higher levels of self-esteem (r = -.44) and lower levels of psychological distress (r = -.32). Of the four social factors, only contact with able bodied people demonstrated significant relations to adjustment, and these were not particularly strong correlations.

In a study with a similar theme, McIvor, Riklan, and Reznikoff (1984), examined the relation between depression and social support in 120 MS patients. The Perceived Social Support Inventory (family based and friends based) was used to assess social support. Strong relations were found between the two perceived social support variables and depression (family based r = -.60, friend based r = -.71). These correlations were comparatively stronger than a number of other factors including age, length of illness, level of impairment, and course of illness. When all factors were subsequently entered into a stepwise forward multiple regression analysis, they accounted for 65% of the

variance in depression. (Unfortunately no other details about this analysis are provided.) McIvor et al. suggested that the more depressed people are, the greater the likelihood that they will perceive themselves as having little or no social support. They asserted that the loss of important social relationships may contribute to depression in people with MS, by evoking a grief reaction. Thus, social support was posited to have a reciprocal relationship with depression.

Foote, Piazza, Holcombe, Paul, and Daffin (1990) examined the relationship between social support, hope and self-esteem, in 40 people with MS. Social support was assessed using the Personal Resources Questionnaire, Part II. A significant association was found between social support and hope, and between social support and self-esteem. Stronger social support was related to higher levels of hope and higher self-esteem. The study had limitations because of its descriptive nature and the mail survey design which attracted a poor response rate (53%).

In an investigation concerned with the prediction of extreme psychological distress, Long and Miller (1991) studied the role of social support in suicidal tendency among 147 people with MS. The study considered the relative predictive value of various factors on suicidal tendency, including social support, hopelessness, fear of death, religiosity, progression of disease and demographic characteristics. Social support was assessed, using original brief scales, in several contexts: family support, friends support, support from the MS Society and clergy support. Initial correlations revealed no or weak associations between suicidal tendency and a number of factors, including MS Society support and clergy support, and they were excluded from subsequent analyses. In a multiple regression analysis which included eight independent variables (two social support variables, two fear of death variables, three religiosity variables and hopelessness), only hopelessness was significantly related to suicidal tendency. However, in a second regression, which included the three strongest predictors from the first analysis (hopelessness, self-perceived religiosity, and family support) each variable demonstrated a significant relation with suicidal tendency. Long and Miller suggested that people with a lack of family support, who are hopeless, and perceive themselves as less religious may be at risk for contemplating suicide. The study has advantages in

considering a number of factors that may contribute to suicidal tendency in people with MS. However, it also has some limitations. Firstly, the findings may be influenced by response bias. Of the 400 people that were mailed a questionnaire, only 147 returned them. Secondly, reducing the number of variables in the second regression appeared to have been a decision made a posteriori, and was therefore one which highly increased the probability of obtaining significant findings. Thirdly, the causal relation of the variables could not be confirmed because of the cross-sectional design of the study.

Wineman (1990) examined the relationships among social support, functional disability, perceived uncertainty, and psychosocial adaptation in 118 people with MS. A modified version of the Social Network List and Support System Scale, providing positive and negative support measures, was used to assess social support. Two path models were tested. The first included depression as an outcome measure of psychosocial adaptation, and the second included purpose in life. In both models, supportiveness, unsupportiveness and functional disability had direct paths to adaptation, as well as indirect paths to adaptation through perceived uncertainty. The results of the regression analyses found 35% of the variance in depression and 33% of the variance in purpose in life was explained by age, sex, social status, supportiveness, unsupportiveness, functional disability, and perceived uncertainty. In the path analysis with depression as the outcome, direct relations between unsupportiveness and depression, unsupportiveness and uncertainty, perceived uncertainty and depression, and functional disability and depression were all supported. The results from the path analysis with purpose in life as the outcome were similar, with the exception of a significant direct relation between supportiveness and purpose in life. However, an indirect relation between functional ability and adaptation (both depression and purpose in life) through perceived uncertainty was not found. These findings provide support for the role of social support in adaptation to MS. Wineman asserted that when social interactions are perceived as unsupportive, people are more likely to experience uncertainty, along with depression and a weaker purpose in life. The study makes an important contribution to the literature because of its well conceived conceptual model and multivariate approach to analysis. However, the use of purpose in life as an adaptational outcome is debatable.

Although the mental health and purpose in life constructs are statistically related, it has been argued that conceptually they are quite different (Zika & Chamberlain, 1992). The theoretical orientation that guided the creation of the Purpose in Life Test regards meaning in life as an individual difference or dispositional factor, rather than as a state of well-being.

Zeldow and Pavlow (1984) focused on the relation between deterioration in physical functioning as a result of MS and social support. In a sample of 81 MS patients, the relative influence of physical health status, life stress, duration of illness and demographic variables on social support was examined. Social support was assessed using a 5-point scale measuring frequency of meaningful social contacts. Results from a stepwise multiple regression showed that physical health status was the only variable that was significantly related to social contacts. People with the highest frequency of social contact were those who had the lowest level of physical dysfunction. Zeldow and Pavlou proposed that worsening MS is associated with a number of psychological and social difficulties, including a decline in social contacts. Although the findings support an association between social support and physical dysfunction, the direction of the causal relationship can not be established from the cross-sectional data.

In a recent descriptive investigation by Gulick (1994) the relationship of social support to activities of daily living (ADL) was examined. Two hundred people with MS completed several measures including the Norbeck Social Support Questionnaire and the ADL Self-care scale for Persons with MS, in a mail-back survey. Perceived social support was assessed in four functional areas: affect, affirmation, aid, and information. ADL function was evaluated with four subscales: motor, socializing/recreation, sensory/ communication and intimacy. Correlations between separate ADL functions and social support categories were low to moderate, with a few significant associations. Total ADL function had a positive and significant association with affirmation for women. The findings suggested that the association between ADL and social support was not strong and varied according to gender and marital status. Unfortunately, the small number of married men (n = 13) in the study decreased the likelihood of significant correlations. Further, the study had a low response rate (200 out of 800

letters sent) and may therefore not be a representative sample.

As part of a descriptive study, Eklund and MacDonald (1991) assessed 125 people with MS on several aspects of social support, using an original measure. Participants reported their relationships with friends, family, marital partners, physicians, and support staff as generally quite satisfactory. Many participants indicated that their primary relationships had changed since their diagnosis with MS; 54.8% with spouses, 52.9% with other family members, and 39.2% with close friends. However, respondents rated the changes as positive about half of the time.

In general, the studies in this section provide evidence to suggest that social support changes as a result of having MS, and that stronger social support is related to better psychological outcomes in people with MS. Stronger social support has been related to higher self-esteem (Foote et al., 1990; Maybury & Brewin, 1984), lower psychological distress (Maybury & Brewin, 1984), lessened depression (McIvor, 1984), more hopefulness (Foote et al., 1990) and stronger purpose in life (Wineman, 1990). Conversely, unsupportiveness has been associated with depression and uncertainty (Wineman, 1990), as well as with suicidal tendency (Long & Miller, 1991). Zeldow and Pavlow (1984) concluded that people with the worst physical disabilities had the least amount of social contact. Gulick (1994) found a weak to moderate association between social support and ADL function. Finally, Eklund and MacDonald (1991) reported that social relationships changed as a result of diagnosis with MS, but remained generally satisfactory.

Social support was conceptualised and measured differently in each of the studies, which makes it difficult to draw any firm conclusions about its role in MS adjustment. In the following chapter, the definitions, dimensions and measurement of social support will be discussed in more detail.

DISPOSITION

As mentioned in chapter 1, the early research considered whether people with MS had

a particular set of personality characteristics that distinguished them from comparison groups. The dimensions of what should be regarded as personality has changed over the years, and has varied from study to study. The recent trend in health psychology research is to consider personality in terms of relatively enduring individual differences such as self-esteem, locus of control, sense of coherence and hardiness. (Schaubroek & Ganster, 1991). A few recent studies have examined personality (or dispositional) factors that may influence the way people cope with, react and adapt to MS. Like the studies on social support, they generally include a number of different constructs, and can be most sensibly discussed within the conceptual framework of adaptation to chronic illness.

Halligan and Reznikoff (1985) studied the relation of health status in MS to locus of control, body image, and depression. Participants were three groups of 20 MS outpatients representing three illness categories: early-stage (less than 5 years), middle-stage (5-15 years) and long-term (15 or more years). Locus of control was assessed with the Rotter Internal-External Scale, modified to include six health items. Internal locus of control was negatively related to depression and high body-image barrier, but was generally not related to disease duration. However, an analysis of the six health-related LOC items demonstrated a trend towards greater externality relative to increased illness duration. Halligan and Reznikoff suggested that people with MS realistically experience a gradual loss of control over their disease. The study examined some interesting relations, but contributes little information beyond some simple correlations.

In a very comprehensive investigation, Brooks and Matson (1982) studied the long-term adjustment process of 103 people with MS. Participants completed mailed questionnaires, containing measures of socio-demographics, disease-related, medical and social-psychological variables, at two data collection times, seven years apart. A non-MS comparison group followed the same procedure. The primary focus of the study was to examine which variables (including locus of control) explained changes in self-concept from time 1 to time 2. For the MS group, internal locus of control was positively related to changes in self-concept and mobility, and negatively associated with number of symptoms experienced. This study had an advantage in examining the

adjustment process using longitudinal data, over a seven year period. However, the findings are limited because only one aspect of adjustment was included. Other features of adjustment such as depression, satisfaction with life and so on would have strengthened the design.

Hickey and Green (1989) examined the ways in which people with MS cope with their illness, with an emphasis on gender differences. Forty-five members of the Ireland MS Society, completed mailed questionnaires, containing measures to assess health locus of control, coping, depression and hopelessness. The Multidimensional Health Locus of Control Scale (MHLC) was used to evaluate three dimensions of health related control. Only one dimension of the MHLC (powerful others health locus of control) showed a significant difference for females and males, with men having the higher scores. Both men and women tended to have an external health locus of control orientation. For both females and males, internal health locus of control was negatively associated with hopelessness. Hickey and Greene suggested that people with MS may be prone to depression and hopelessness because of their external health locus of control orientation and their inability to effectively use psychological defence mechanisms. However, they acknowledged that depression and hopelessness may be a result of disease lesions rather than being psychosocially determined.

Devins, Seland, Klein, Edworthy, & Saary (1993) examined the effects of illness-related variables and personal control on psychosocial well-being. A range of measures were completed by 94 people with MS on three occasions over 18 months. Personal control in relation to 13 life domains was assessed using the Control Ratings Scale. Variables were found to be generally stable over the 18 months period, and hence only findings based on data collected in the first wave were reported. In a multiple regression analysis, variables were entered into the equation in a theoretically determined order. Stressful life events was entered as a control variable, followed by course of illness, functional deficits, physical disabilities, illness intrusiveness, and personal control, in sequence. After controlling for recent life events, physical disabilities, illness intrusiveness and personal control were each significantly and uniquely associated with psychosocial well-being. Increased personal control was related to better psychosocial

well-being. The study had strengths in its explicit conceptual framework and well conceived analysis.

In an investigation by Pollock, Christian, and Sands (1990), adaptation to chronic illness was examined in three different diagnostic groups: MS, rheumatoid arthritis (RA), and hypertension (HPT). Of the 210 people who participated in the study, 126 were diagnosed with MS, 42 with RA, and 44 with HPT. The study was based on an explicit theoretical model of adaptation to chronic illness which included dispositional hardiness as a key variable. Subjects completed a range of measures including physiologic function scales, the Mental Health Inventory, the Health-Related Hardiness Scale, and the Margin in Life Scale. Psychological adaptation was viewed as good mental health and the ability to tolerate changes and stresses. In the total sample, hardiness was significantly correlated to both physiologic adaptation and psychological adaptation. Further, the presence of hardiness was not significantly different in the three groups. The findings support the hardiness characteristic as an important factor in the adaptation process. It is commendable that an explicit theoretical model provided the framework for this study. However, since the process of adaptation presumably happens over time, it is debatable whether the cross-sectional data is an appropriate test of the model.

Overall, relatively few recent studies have explored the role of dispositional variables on the MS illness process. The studies that do involve a dispositional variable have focussed on sense of control over one's illness, and include variables such as locus of control and hardiness. People with MS tend to have an external health locus of control orientation (Hickey & Green, 1989), and externality has been found to increase with illness duration (Halligan & Reznikoff, 1985). Having an internal orientation appears to be beneficial, demonstrating a negative association with hopelessness (Hickey & Green, 1989) and number of symptoms experienced, and a positive relation to mobility and changes in self-concept (Brooks & Matson, 1982). A strong sense of personal control over life domains was associated with better psychosocial well-being (Devins et al., 1993). Pollock et al. (1990) found hardiness to be associated with both physiologic and psychological adaptation.

SUMMARY AND CONCLUSIONS

It is clear that the relationship of psychosocial factors to MS is complex. The combined stress studies suggest that intense stress may contribute to disease onset or exacerbation. However, this hypothesis can not be confirmed given the retrospective and cross-sectional designs of the majority of the investigations. Generally, the studies on psychological well-being suggest that people with MS are prone to depression and other emotional disturbances as well as decreased quality of life. Further, emotional disturbance appears to be associated with illness activity, increasing during times of disease exacerbations. As with the stress studies, many use cross-sectional designs and do not examine change in both disease and well-being across time. As mentioned previously, at least some of the psychological scales that have been used in these investigations are confounded with somatic content, possibly exaggerating the severity of emotional distress.

The studies reviewed on social support and disposition come mainly from research on the adaptation process in MS. A number of different outcome variables have been used to represent adaptation, and this obviously has a bearing on conclusions made about successful adaptation. Most studies on adaptation, are not really examining adaptation, since they use cross-sectional data and do not assess change over time. Relatively few studies have been published about MS that include social support or dispositional variables. Those reviewed here suggest that both social support and certain aspects of disposition may have a beneficial role in the adaptation process.

Recent research on the psychosocial aspects of MS has been diverse in terms of focus, complexity, and research methodology. Many studies have been mainly descriptive, focusing on one or more psychosocial factors in people with MS. Some studies have progressed further, by relating psychosocial factors to disease activity. However, studies are scarce that examine how MS impacts on psychosocial factors or conversely, how the psychosocial factors exert their influence on MS. At the conclusion of his major literature review on psychological aspects of MS, VanderPlate (1984) commented: "Psychological investigators have studied psychological factors without adequate

attention to the disease process as content" (p. 268). Even very recently, after a comprehensive review of the literature, Devins and Seland (1987) argued the need for studies to focus on the psychological mechanisms by which MS impacts on emotional outcomes.

Overall, many of the studies on the psychosocial aspects of MS can be criticised for not being grounded in good conceptual models. Many studies are descriptive, and relations between variables have tended to be explored at a superficial level. Little attention has been given to the relative influence of direct versus moderating influences on the illness process. Of the models that have been developed, few contain the range of constructs or variables needed to understand the bigger picture.

Given the literature in this field, there is a need for research that can look at a number of relevant psychosocial factors simultaneously and evaluate their role in the MS illness process. This would require a model that can investigate both static and changing relationships, and can separate psychosocial processes from disease processes. The present study will attempt to expand upon previous work in the area by developing a comprehensive conceptual model, described in the next chapter, that addresses the issues mentioned above.

CHAPTER 3

DEVELOPMENT OF THE THEORETICAL MODEL

This chapter focuses on the theoretical model used in the present study. The chapter first discusses the rationale for the inclusion of constructs and their associated variables in the model, then describes the predicted functional relationships of the constructs. It then considers the implications of testing such a model in terms of analytic strategies. Finally, it presents the research aims of the study.

Two main issues were considered when developing the current model. Firstly, the factors that best represent what the model is attempting to explain (content), and secondly, how the factors relate to each other (process). In the first major section, content issues relevant to the present model will be discussed, followed by an elaboration of each construct and variable included in the model. The second major section will consider the functional relationships depicted in the model.

The present model endeavours to examine the multiple sclerosis illness process over time, taking into account changing psychosocial and physical factors. In contrast to this comprehensive framework, previous complex psychosocial models of MS have tended to have a narrower focus. For example, some have considered adaptation to MS (Perry, 1992; Pollock, 1986; Wineman, 1990), and others have been concerned with the psychosocial impact of MS (Devins & Seland, 1987; Devins et al., 1993).

The theoretical model in the present study is not an attempt to take any one previous model and develop it further. Rather, it synthesizes elements from a range of theoretical frameworks. In selecting appropriate constructs for the model, the literature pertaining to psychosocial factors in MS (reviewed in chapter 2) and the theoretical models incorporated in that research, as well as the broader conceptual issues concerning chronic illness were considered.

As discussed in the previous chapter, research concerned with the role of psychosocial factors in multiple sclerosis suggests that certain factors are worthy of consideration in terms of the illness process. Stress was found to be related to disease activity in MS (Franklin et al., 1988; Grant, Brown, et al., 1989; Warren et al., 1991). People with MS were found to be more prone to depression and other emotional disturbances than comparison groups (Minden et al., 1987; Schubert & Foliart, 1993; Whitlock & Siskind, 1980; Rabins et al., 1986). Certain dispositional characteristics were reported to be associated with better adaptation to MS (Halligan & Reznikoff, 1985; Hickey & Green, 1989; Pollock et al., 1990), and stronger social support was found to be related to better psychological outcomes in people with MS (Maybury & Brewin, 1984; McIvor et al., 1984; Wineman, 1990). Overall, research suggests that changes in physical status and disease-related factors are interwoven with psychosocial factors throughout the course of multiple sclerosis.

Interpretations of the life stories of people with MS confirm the impressions of the more quantatively based studies. Robinson (1988) suggested that physical status, social relationships, personal characteristics and situational events combine to affect adaptational outcomes. He stated:

> The weight of the existing evidence suggests that a diffuse combination of personal characteristics, the viability of personal and social relationships preceding the onset of the disease, and the nature and type of personal and social events occurring after the onset, are better predictors of adaptation or adjustment than the progress of the disease itself. (p. 49)

Therefore, quantitative and qualitative research strongly suggest that theoretical models of the MS illness process should contain a range of psychosocial factors. Further, MS involves complex physical processes, and hence a range of physical status indicators are needed in a model.

The model in the present study attempts to explain how changes in stressors, psychological states, and physical health, as well as more stable dispositional and social support factors, relate during the short term course of multiple sclerosis. Although this

framework allows for the examination of several factors that interrelate in the MS illness process, it does not constitute a formal causal model suitable for testing by structural equation analysis. A number of hypotheses will be tested, focusing on various relations in the model, however, the model in its entirety will not be tested. The reasons for embracing this orientation will be discussed in the next chapter.

FACTORS IN THE THEORETICAL MODEL

The present model comprises five constructs: psychological well-being, stressors, disposition, social support and physical health status. It is clear from previous studies that any one of these constructs can be represented by different variables, depending upon the theoretical framework that is adopted. In particular, psychological well-being and dispositional variables often overlap. It can be extremely difficult to differentiate a stable characteristic of the individual from a relatively stable psychological state. For example, purpose in life has been regarded as both an indicator of well-being and as a dispositional trait. Similarly, negative affect has been treated as both a transient emotional state and a dispositional trait. To make matters more confusing, two variables can be strongly correlated but conceptual arguments suggest that they represent two different constructs. In the following section the conceptual reasoning that guided the definition of constructs and variables, and their placement in the model will be addressed. To provide a more in depth description of the constructs contained in the model, and the variables selected to represent them, each will be discussed in turn.

Psychological well-being

In the present study, the term 'psychological well-being' is used quite broadly to include the usual three dimensions of well-being (positive affect, negative affect and life satisfaction) as well as three specific characteristics of negative affect (depression, anxiety, and hopelessness). Over the years researchers have held differing views about the structure of psychological well-being. According to Heady, Kelley, and Wearing (1993) some researchers have advocated a single dimension of well-being (happiness), some a two dimensional solution (negative and positive affect), but most have upheld

a three dimensional approach comprising negative affect, positive affect and life satisfaction. Negative affect is a general factor of subjective distress and encompasses a range of aversive mood states. Positive affect is a general factor of subjective pleasure and reflects enjoyable mood states. Life satisfaction is a global assessment of all aspects of a persons life considered together. It is generally agreed that negative and positive affect provide an emotional assessment of well-being, whereas life satisfaction provides a cognitive assessment. Although the affective-cognitive distinction has not been fully substantiated by research, the conceptual distinction between what makes people happy or unhappy versus what makes people satisfied is important (Chamberlain, 1988).

The three dimensional approach to well-being is utilised in the present study. All three dimensions of well-being are important to consider in relation to the course of multiple sclerosis. Most prior studies focusing on psychological states as they relate to MS have considered only negative emotional states. However, positive emotional states may also have an impact on the illness process. Research evidence from studies considering the beneficial influence of positive emotional states on physical health has been generally supportive (Edwards & Cooper, 1988). How satisfied people feel about their lives is clearly an important factor to consider in people with a chronic illness. Persons with MS may be required to make many changes in their lifestyle as their illness progresses, and this is likely to affect their degree of life satisfaction.

The two major dimensions of affect, positive affect and negative affect, are only weakly correlated, indicating that they are relatively independent of one another (Watson, Clark & Tellegen, 1988). However, within each general factor, various related affects tend to co-occur (Watson & Clark, 1992). The conceptual distinction between positive and negative affect is supported by research that has found the variables to possess different correlates (Chamberlain, 1988; Watson, 1988; Watson & Pennebaker, 1989).

Psychological well-being is a stable factor, but is also responsive to changes in life circumstances (Chamberlain & Zika, 1990). The high stability of well-being has influenced some researchers to regard it as a dispositional trait, as well as a mood state.

Trait negative affect is considered to be conceptually similar to neuroticism (Costa & McCrae, 1987) and has demonstrated strong correlations with self-reported health complaint measures (Watson & Pennebaker, 1989). However, it is not consistently associated with actual long term health status and can therefore be regarded as a nuisance factor in health research (Watson & Pennebaker, 1989).

In the present study, where the emphasis in on short term change, affect is assessed only as an emotional state. The exclusion of trait negative affect is less problematic in studies that use self-report symptom measures in conjunction with other indicators of health (Watson & Pennebaker, 1989), as is the case in the current study.

As mentioned previously, the present study also includes three specific types of negative affect: depression, hopelessness, and anxiety. These variables were selected because of their relevance to the MS illness process. As noted earlier, depression has been regarded both as a reaction to having MS and a direct physical effect of the disease. Previous research has found people with MS to suffer from a high incidence of depression (Schubert & Foliart, 1993). Furthermore, findings suggest that depression may be related to illness activity, becoming more pronounced during exacerbation periods (Dalos et al., 1983). Hopelessness can be considered a specific type of depression that transpires when "...the individual's expectation that highly desired outcomes will not occur or that highly aversive outcomes will occur and that no response will change the likelihood of occurrence of these outcomes." (Abramson, Metalsky, & Alloy, 1993, p. 182). In early MS research based on case studies, MS patients were described as having feelings of helplessness and giving up when confronted with difficult life experiences (Mei-Tal et al., 1970). In a more recent investigation, hopelessness was found to be elevated in people with MS (Hickey & Greene, 1989). Finally, anxiety, an emotional state characterised by fear and dread, seems appropriate to consider given the uncertainties inherent in the MS illness. In an early study, Philippopoulos et al. (1958) described MS patients as chronically anxious, though they viewed anxiety as a personality characteristic rather than a reaction to the illness. More recently, anxiety was found to be at higher levels in MS patients than in spinal cord patients (Rabins et al., 1986).

Stressors

Holmes and Rahe (1967) made a strong impact on the stress field with the development of a life-change framework for stress. They conceptualised stress in terms of social adjustment, or the ability to accommodate to a life event, regardless of the desirability of the event. Holmes and Rahe proposed that life-change events evoke faulty adaptive efforts that consequently lower bodily resistance and increase the likelihood of disease occurrence (Holmes & Masuda, 1974). The effects of life events were viewed as cumulative: the more life events experienced, the greater the probability of illness resulting. Studies, based on differing populations and a wide range of disorders, have demonstrated modest correlations of between .2 to .3 for the life events-illness relation (Rabkin & Struening, 1976; Schroeder & Costa, 1984). However, the accuracy of this association has been challenged on the basis that life events measures may be confounded with psychological adjustment and neuroticism, thereby inflating the correlations (Schroder & Costa, 1984).

An alternative stress framework, proposed by Lazarus and his colleagues (1984), defined stress..." as an inharmonious fit between the person and the environment, one in which the person's resources are taxed or exceeded, forcing the person to struggle, usually in complex ways, to cope" (p. 376). Lazarus argued that the life events approach to stress was limited because it overemphasised change, and failed to consider the individual significance of events, or the person's coping resources and liabilities. Furthermore, as noted above, life events demonstrated weak explanatory power in regard to health outcomes.

In contrast to the life events stress framework, Lazarus and his colleagues proposed an approach that recognised the importance of relatively minor stressors, and labelled these occurrences daily hassles (Kanner, Coyne, Schaefer, & Lazarus, 1981). Hassles are defined as "...experiences and conditions of daily living that have been appraised as salient and harmful or threatening to the endorser's well-being" (p. 376). It has been speculated that life events may influence the pattern of daily hassles, and that hassles may affect health outcomes independently from life events (Kanner et al., 1981).

Research has found minor events to be a more powerful assessment of stressors than life events in predicting outcomes such as health (Delongis, Coyne, Dakof, Folkman, & Lazarus, 1982; Weinberger, Hiner, & Tierney, 1987) and psychological distress (Burks & Martin, 1985; Kanner et al., 1981; Chamberlain & Zika, 1990). Hassles have also been found to be contextually sensitive in defining individual stress experiences (Chamberlain & Zika, 1990; Gruen, Folkman, & Lazarus, 1988). However, the measurement of hassles has also been criticised for being confounded with symptoms of psychological disorder (Dohrenwend, Dohrenwend, Dodson, & Shrout, 1984).

The present study incorporates both the major events and minor events approach to stress. It is believed that these approaches can complement one another in providing important information about the role of stressors in multiple sclerosis. Empirical studies have found hassles and life events to be only modestly correlated (Warren, 1990), which suggests that they are capturing different aspects of the stress experience.

It has recently been proposed that, for an individual, only certain major events would result in vulnerability to a health-related disorder (Monroe & Simons, 1991). In the present study participants were asked to identify events that have had a recent impact on their lives. It is presumed that they will recognise events that are most important to themselves, and therefore those that may result in psychological distress. The desirability of the event is not specified, since it is assumed that any major life-change requires adaptation. Most studies focusing on the role of stress in MS have utilised the major life events approach to stress, rather than the hassles approach. Life events have been found to be associated with disease exacerbation (Franklin et al., 1988; Grant, Brown, et al., 1989), and poorer well-being (Zeldow & Pavlou, 1984).

The minor stressors approach has also been incorporated in the present investigation. Since few studies have considered the association between hassles and the MS illness process, this will extend the information available in this area. It is likely that living with a chronic illness produces stressors in many areas of a person's life. Particularly when the disease results in permanent disability, as is often the case in MS, an increase in daily stressors might be expected. It is also possible that the build up of minor

stressors precedes exacerbations of the illness. In people with MS, lower levels of hassles have been associated with better life satisfaction and more positive self-esteem (Perry, 1992). During disease exacerbation, people have reported more intense hassles (Warren et al., 1991).

Disposition

Disposition or personality is defined as a relatively stable individual difference. Research findings suggest that personality has a causal role in the development and progression of disease, although conceptual models relating these factors are controversial (Friedman, 1990). One possible mechanism is that people with particular dispositional qualities are better able to cope with stress, thereby buffering the potential harm of stress on health. Lazarus and Folkman (1984) asserted that two person attributes, commitments and beliefs, influence the cognitive appraisal process, enabling more effective coping. They argued that personal control beliefs and existential beliefs are powerful determinants of how a person perceives a stressful encounter. Two other constructs that have been proposed to moderate the impact of stress on health outcomes are sense of coherence (Antonovsky, 1979) and hardiness (Kobasa, 1979). Both constructs are comprised of interrelated factors, and assessments rely on composite measures. Although this has some advantages, using a composite measure can result in information being lost and greater ambiguity in explaining findings (Carver, 1989).

The present study included four dispositional factors that are similar to those reflected in the sense of coherence and hardiness constructs, and are similar to the person characteristics proposed by Lazarus and Folkman (1984). These are: dispositional optimism, meaning in life, locus of control, and health locus of control. Factors of this type are regarded as characteristics that determine a person's expectancies about life and their future; more specifically, perceiving life with an optimistic orientation, finding meaning in life experiences, viewing life with a belief that experiences can be controlled or influenced, and having a sense of control over one's health.

The sorts of dispositional factors considered in this study, have been implicated in the

adjustment process in multiple sclerosis. After considering 400 life stories of people with MS, Robinson (1988) suggested that the illness challenges people to make sense out of their future and that certain personal attributes appear to contribute to a favourable outcome. He asserted:

> In relation to the disease faith in oneself may be the key, in the last analysis, to keeping an intact identity. This faith may well be associated with the degree to which individuals feel themselves drowned by their disabilities, or have the capacity to rise above them, and feel able in some sense to control their effects on the personally important aspects of life. (p. 135)

Dispositional optimism

Dispositional optimism involves an orientation towards life that assumes that good things will happen. The construct evolved out of psychological motivation theory and posits that people who see desired outcomes as attainable will continue to exert effort, whereas people who view desired outcomes as unattainable will reduce their effort and eventually give up (Scheier & Carver, 1987). According to Scheier and Carver (1987) an optimistic orientation may positively influence well-being in two ways; by determining the type of coping strategies a person uses, and by having a direct effect on physiological functioning. Empirical evidence has generally supported a positive association between dispositional optimism and health outcomes (Marshall & Lang, 1990; Reker & Wong, 1985; Scheier & Carver, 1985, 1987, 1992).

The construct has, however, been criticised on both methodological and theoretical grounds. Smith, Pope, Rhodewalt, and Poulton (1989) asserted that the Life Orientation Test (LOT), the measure commonly used to assess dispositional optimism, had limited discriminant validity in relation to measures of neuroticism. Sheier and Carver (1992) responded to the criticism with a convincing counter-argument, asserting that part of the neuroticism construct is actually pessimism. To examine variable overlap, they factor analysed the items of the LOT combined with neuroticism and trait anxiety measures, and extracted an Optimism factor. The Optimism factor correlated in the .80s with the raw LOT scores, and uniquely predicted a significant amount of variance in a variety

of health outcomes.

Two theoretical criticisms of dispositional optimism have been advanced. Firstly, the assumption that high levels of optimism are beneficial to a person's well-being has been challenged. It has been proposed that there are health risks, as well as benefits, associated with having an optimistic orientation (Tennen & Affleck, 1987). However, there is not strong empirical evidence to support this position (Scheier & Carver, 1992). Secondly, the assumption that the structure of dispositional optimism (as measured by the LOT) is unidimensional has been disputed (Schwarzer, 1994). Schwarzer asserted that two distinct and moderately correlated dimensions, optimism and pessimism, are represented in the scale. Since these dimensions appear to relate to different traits and emotions, he questioned the appropriateness of treating optimism as a unidimensional construct. However, the contention that dispositional optimism is more usefully considered in a two dimensional framework is very current, and the validity of this perspective is yet to be established.

Optimism seems a meaningful dispositional factor to consider in people with MS. In an illness with a progressive course and no cure, such as MS, it is important to understand how optimism relates to psychological functioning. As mentioned in chapter one, in the late nineteenth and early twentieth centuries people with MS were regarded as morbidly optimistic. Although this view is no longer held, little is known about how an optimistic orientation relates to the course of the illness.

Meaning in life

Meaning in life can be defined as "...the cognizance of order, coherence, and purpose in one's existence, the pursuit and attainment of worthwhile goals, and an accompanying sense of fulfilment" (Reker & Wong, 1988, p. 221). The concept of meaning in life has its foundations in existential psychiatry and psychology. In particular, the writings of Victor Frankl made a major contribution towards the conceptual development of meaning in life. Frankl's ideas and insights emerged out of his experiences as a prisoner in a Nazi concentration camp. He asserted that life has meaning under all

conditions, even those of extreme suffering (Frankl, 1959, 1967). Furthermore, Frankl argued that when a person is impeded in his or her search for meaning, existential frustration will occur, and will eventually lead to psychopathology.

In recent decades, the role of meaning in life has emerged in stress and coping frameworks. Lazarus and DeLongis (1983) proposed that patterns of commitment, a similar concept to meaning in life, influences the way situational events are appraised in terms of their impact on well-being, and affects the way these events are managed. Kobasa (1979) used the term hardiness to describe a personality structure that moderates the effect of stress on health outcomes. The commitment component of hardiness is conceptually similar to meaning in life. Antonovsky (1979) originated the term sense of coherence to describe a personality construct which has been proposed as insulating people against the potential harm of stressors on health. The construct encompasses meaningfulness as one of its three components. Antonovsky asserted that people with a strong sense of coherence perceive their experiences as meaningful, and expect that their future experiences will be meaningful.

Zika and Chamberlain (1992) reviewed a number of recent studies that examined the relation of meaning in life to aspects of mental health. They concluded that meaning in life is consistently related to positive mental health outcomes, whereas meaninglessness is associated with pathological outcomes. Although meaning in life and psychological well-being are strongly related, exactly how life meaning exerts its effects on well-being has not been fully established (Zika & Chamberlain, 1992).

There is a paucity of specific research on the role of meaning in life on the course of multiple sclerosis, but its relevance seems self-evident in the MS context. Lazarus and Folkman (1984) suggested that when individuals suffer from serious physical harm, existential beliefs that create meaning out of life can make a situation bearable that might otherwise be overwhelming. Conceptual arguments supporting the importance of personal meaning in relation to successful aging are also applicable to the chronically ill. Wong (1989) asserted:

> It is perhaps the [sic] one of the few areas in which an individual can experience

> continued personal growth in the face of losses, pain and physical decline. A sense of meaning may be particularly important for the frail and the chronically ill, because it is perhaps one of the few sources of motivation and life satisfaction that transcend physical constraints. (p. 519)

This last point is very relevant to the experiences of people with MS. Particularly for individuals who have deteriorated in physical functioning, maintaining a strong sense of life meaning may be crucial to their well-being, and may have a role in preventing further physical deterioration.

Locus of control and health locus of control

Locus of control, an expectancy factor related to internal versus external control of reinforcement, emerged out of Rotter's social learning theory (Rotter, 1966). It is defined as:

> ...the degree to which persons expect that a reinforcement or an outcome of their behavior is contingent on their own behavior or personal characteristics versus the degree to which persons expect that the reinforcement or outcome is a function of chance, luck, or fate, is under control of powerful others, or is simply unpredictable. (Rotter, 1990, p. 489)

Locus of control (LOC), considered a relatively stable cross-situational individual difference, has been of great interest to social scientists for several decades (Rotter, 1990).

Personal control is a component of Kobasa's (1979) hardiness construct, and Antonovsky's (1979) sense of coherence personality structure. In both cases, personal control is proposed to buffer the impact of stress on health outcomes. However, Antonovsky's concept of control is somewhat different from Rotter's internal-external LOC, because control does not necessarily lie in a person's own hands, but may come from any legitimate source (Antonovsky, 1979).

The relation of LOC orientation to psychological well-being has received attention from researchers. A number of studies have found LOC and perceived control to either

moderate the impact of stressors on adaptational outcomes, or to directly affect well-being (Zika & Chamberlain, 1987).

Research has also focused on the relation of internal-external expectancies to health-related behaviours and outcomes (Strickland, 1978). Strickland made an insightful comment about the relevance of LOC to health issues:

> One would expect that internal, in contrast to externals, would be more sensitive to health messages, would have increased knowledge about health conditions, would attempt to improve physical functioning, and might even, through their own efforts, be less susceptible to physical and psychological dysfunction. (p. 1193)

Early findings were inconsistent, but generally supported the position that when confronted with health problems, internally orientated individuals engage in more adaptive responses than externally orientated persons (Strickland, 1978).

In response to the inconsistent results in the LOC and health literature, which was partly attributed to the use of different measures, health locus of control scales were developed (Lau, 1988). Health LOC focuses on "The degree to which individuals believe that their health is controlled by internal versus external factors... " (Wallston & Wallston, 1982, p. 68). Research using health LOC scales has focused almost exclusively on the relationship of LOC to preventative health behaviours but unexpectedly findings have not confirmed an association (Lau, 1988; Wallston & Wallston, 1982).

However, recently Wallston (1992) modified his position on health locus of control, arguing that health-promoting behaviours are a function of both perceived control over health and valuing of health. Perceived control also has implications for understanding adjustment to chronic illness. For example, Affleck, Tennen, Pfeiffer, and Fifeld (1987) found, in rheumatoid arthritis patients, that personal control over symptoms was associated with less mood disturbance, whereas personal control over the course of the illness was associated with greater mood disturbance.

Personal control has been identified as an important factor in adaptation to multiple

sclerosis. Devins and Seland (1987) suggested that illness-related factors, such as incapacitation and disease activity, can jeopardise a person's ability to exert control, making it less likely that he or she will obtain positive outcomes or avoid negative outcomes.

> The negative emotional impact of MS might, thus be a function of the extent to which relatively severe reductions to personal control may be introduced by illness-related factors and the extent that coping efforts are unable to reverse the intrusiveness produced by these changes. (p. 372)

In the present study LOC was evaluated in two ways, at a general level and in terms of health. People with an incurable chronic illness may generally perceive themselves in control of their lives but, realistically, may not believe they have control over their health. It is important to explore whether the two levels of control function similarly in the MS illness process, or relate in different ways to psychological well-being and physical health outcomes.

Social Support

Since the emergence of social support as a research issue, the construct has been conceptually defined in dozens of ways (Wilcox & Vernberg, 1985). One of the more useful definitions, adapted from Kaplan (Kaplan et al., 1977 cited in Thoits, 1982), describes social support "as the degree to which a person's basic social needs are gratified through interaction with others" (p. 147). There is general agreement among researchers that social support is a multidimensional construct comprised of different types of support resources (Wilcox & Vernberg, 1985). However, the most useful way to categorize dimensions of social support is debatable. More recent research tends to consider the function and quality of beneficial relationships, and may distinguish between emotional support, informational support, tangible support, esteem support, appraisal support, and so on (Schwarzer & Leppin, 1991). Social support has been operationalised by a wide variety of measures, in part a consequence of the considerable divergence in its definition.

Barrera (1986) has described the consistent criticisms found in the social support literature. Firstly, the social support definitions are so vague and broad as to make the concept indistinct. Secondly, there is little consensus among researchers as to how social support should be defined. Thirdly, social support is measured in diverse ways which often appear unrelated to each other. Fourthly, there is a deficiency of consistency in research findings. More recently, Schwarzer and Leppin (1991) also argued that social support research suffers from similar conceptual and methodological shortcomings. Nevertheless, social support has demonstrated important (though inconsistent) relationships with psychological and physical health outcomes (Broadhead et al., 1983; Schwarzer & Leppin, 1989, 1991; Wallston, Alagna, DeVelis, & DeVelis, 1983), and the methodological and conceptual problems appear not to be insurmountable.

There are several conceptual models that depict the process through which social support may exert its effects on health outcomes (Barrera, 1986; Schwarzer & Leppin, 1991). The two models that have been most consistently employed in health research are the buffering model and the main-effect model (Cohen & Wills, 1985). The buffering model posits that social support is only beneficial for persons under stress, and functions by buffering the effects of the stress. The main-effect model propounds that social support is beneficial regardless of whether persons are under stress, and operates by providing positive affect, predictability, stability and self-worth. However, the two conceptual models are not viewed as mutually exclusive (Cohen & Wills, 1985).

Empirical studies, though limited in number, suggest that social support has consequences for psychological functioning in people with MS. Further, research suggests that social support changes over the course of the MS illness (Eklund & MacDonald, 1991; Gulick, 1994). Experiential accounts of persons with MS also emphasise the importance of considering this factor. Robinson (1988) proposed that social context influences and limits the options available to people and also affects their self-perception. In unstructured interviews conducted by Barton, Magilvy, and Quinn (1994), they observed that the issue of social support was consistently expressed.

In the present study perceived, rather than received social support was assessed. Consideration was given to whom people can turn to for support, for which kinds of problems, and how satisfied they feel with their interpersonal relationships (Sarason, 1988). Research supports the position that the way people discern the support available to them may be more important, in terms of health outcomes, than tangible social contacts (Sarason, 1988; Sarason, Sarason, & Pierce, 1990). From a theoretical view "The general sense that one is loved and cared for by others and that these others would help once they are really needed should contribute to psychological and physical well-being" (Schwarzer & Leppin, 1991, p. 102).

Physical health status

In any study examining the relation between changes in psychosocial and physical health factors in people with MS, it is necessary to incorporate variables that represent various aspects of physical health functioning. In the present study physical health status was conceptualised in terms of common symptoms of MS, functional ability/disability, impairment as a result of MS, and changes in overall health.

The World Health Organization definitions for impairment, disability and handicap have a strong bearing on the conceptualization of physical health status for the present study (WHO, 1980). Impairment reflects disturbances at the level of the organ, and is defined as..."any loss or abnormality of psychological, physiological, or anatomical structure or function" (p.47). Disability reflects disturbances at the level of the person, and is defined as..."any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (p.143). Handicap reflects the consequences of impairment and disability for the individual, and is defined as ..."a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal ...for that individual" (p.183).

Therefore, impairment and disability are represented in the physical health realm, in contrast to handicap which is represented in the social sphere. These conceptual

distinctions are important when considering physical health outcomes. A variable may not always be represented by a measure with a similar (in terms of WHO definitions) label. For example, the Kurtzke disability status scale (Kurtzke, 1965) actually provides an assessment of global impairment, rather than disability.

The present study focuses on short term change over a period of months, and therefore the inclusion only of disability and impairment variables, which represent the more stable factors in MS, would be unlikely to capture the more subtle health changes. Consequently, two other aspects of health were also included. Symptoms, which are more likely to fluctuate over short time periods, were considered both in terms of how often a person experiences a particular symptom and in terms of how intensely the symptom is experienced. In addition, the study was concerned with overall health change. People with MS can be affected by usual health concerns in addition to those attributed the disease, such as colds, influenza, injuries and so on, exemplifying a separate aspect of health.

The final issue in regard to health status concerns the way in which health information was collected. Unlike the psychosocial assessments, which were all based on self-report measures, some of the physical health status evaluations were obtained by a physician during physical examinations. This provided an advantage by allowing a greater range of physical health outcomes to be included in the study. For example MS signs, which can only be determined through physical investigation, were assessed in addition to self-reported symptoms. As noted earlier, the inclusion of health status indicators that do not rely on self-report ensures that neuroticism will not obscure the psychological-physical health association (Watson & Pennebaker, 1989).

In some cases, similar or identical measures were completed by both the participant and the physician, providing assessments based on different perspectives. When evaluations concur, greater validity in the assessment can be assumed. The similarity or dissimilarity of self-rated versus physician-rated assessments is an interesting research issue, but one that is not a major focus of the present study.

RELATIONSHIPS IN THE THEORETICAL MODEL

A diagrammatic representation of the theoretical model used in the present study is presented in Figure 1. Direct effects are displayed as solid lines and moderating effects are shown as broken lines. Although the model is original in terms of the set of constructs brought together, the way in which the constructs are proposed to relate is largely suggested by established theory and previous empirical findings. Nonetheless, many of the relations in the model have not been extensively investigated in people with multiple sclerosis.

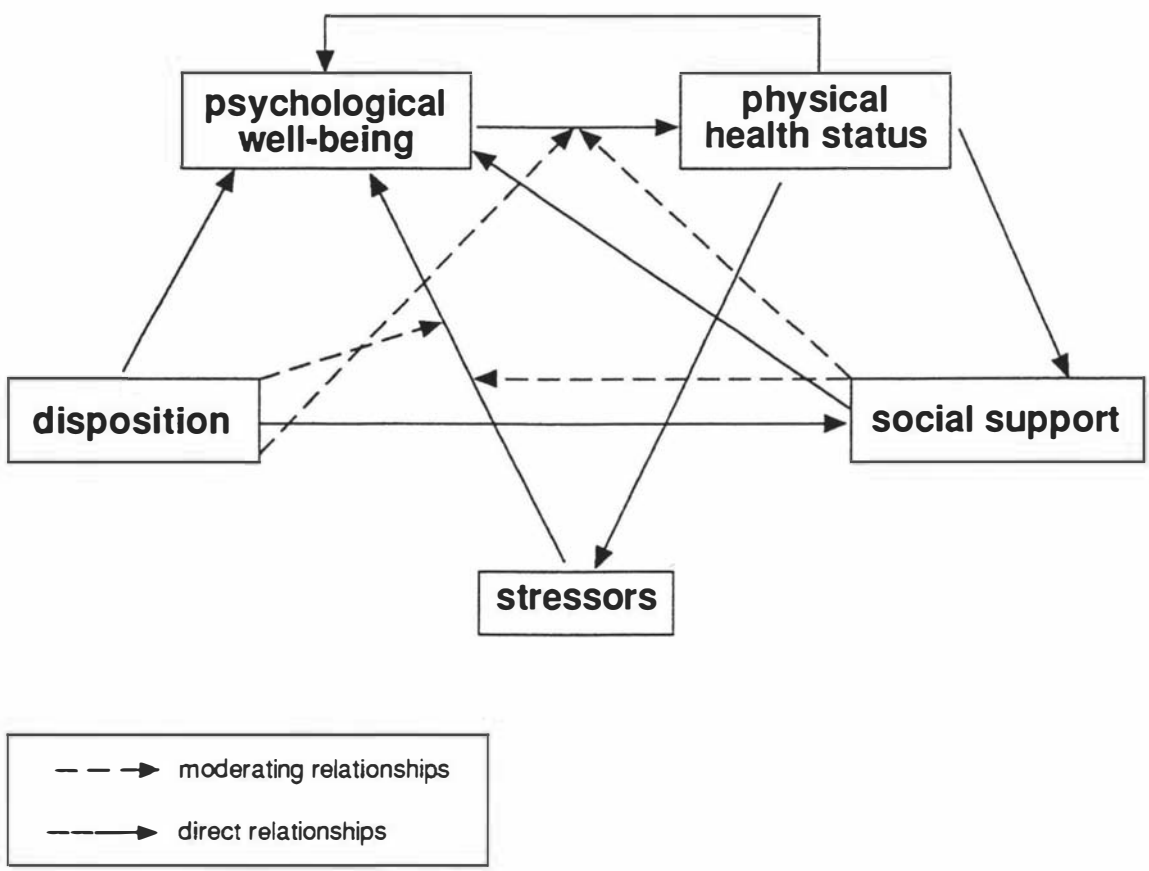


Figure 1. Model relating psychosocial and physical factors in multiple sclerosis.

The processes depicted have two notable features. Firstly, the various moderating relationships reflect the possibility that associations are not the same for all people, but

are influenced by personal attributes or context. Secondly, the model includes a reciprocal relationship (feedback loop) between psychological and somatic factors. This assumes that when there are changes in one factor this will contribute to changes in the other factor, in both directions.

The stress-coping-chronic illness framework developed by Ben-Sira (1984) was particularly influential in suggesting the causes and effects of psychological well-being in the present model. Ben-Sira argued that when people are confronted with demands they perceive as insurmountable (stressors), their emotional homeostasis is disturbed, and that if this is not resolved through successful coping, it can lead to a breakdown in health. He asserted that chronic illness can be viewed as an expression of breakdown and that the characteristics of chronic illness, particularly uncertainty in prognosis, can produce additional stressors which, if not coped with successfully, create further disturbance in emotional homeostasis. This last point is particularly relevant to multiple sclerosis which is a disease characterised by uncertainty. The importance of psychological states in affecting the illness process, is thus a central focus of the current model.

In the present model, psychological well-being is, in a sense, the pivotal factor, since every other factor directly, and sometimes indirectly, influences well-being. Furthermore, well-being is the only factor that directly affects physical health status. Thus, the model posits that well-being functions as a filter for several potential forces. Stressors, disposition, and perceived social support each affect psychological well-being, which, in turn, influences physical health. The view of emotional disturbance as a precursor of somatic health change is supported by the previously mentioned chronic illness framework developed by Ben-Sira (1984), but also by the mental health-social support-health framework proposed by Cohen and Wills (1985), and the stress-coping-adaptation model advanced by Lazarus and Folkman (1984).

Although the model does not depict an association between stressors and health status, as already stated, it is proposed that stressors affect health through their impact on psychological states. Stressors are appraised or experienced, either consciously or

unconsciously, as benign, threatening or harmful, which creates a corresponding cognitive or emotional reaction. The view that people's perception of their stressors trigger an emotional response, has similarities to the primary appraisal process described in Lazarus' coping theory (Lazarus & Folkman, 1984). Emotional reaction ultimately impacts on health, possibly through physiological changes that interfere with immune functioning or through their impact on behavioural patterns that create risky situations in terms of health (Cohen & Wills, 1985). As mentioned in chapter 1, the immune system is implicated in the demyelination process that occurs in MS (Burks, 1992).

In the current model appraisal and coping are not directly depicted, however, it is assumed that both these processes are indirectly represented in the model. For example, when individuals identify their stressors they are using the appraisal process to discern neutral situations from stressful situations. Further, although the way people cope (coping styles) are not included, it is assumed that the effectiveness of their coping is reflected by their psychological well-being and their physical health status. In the main the model was developed with an emotional rather than a cognitive orientation, and, as the case with any model, it was necessary to limit its complexity.

The present model posits that individual difference factors (disposition and perceived social support) influence health outcomes by assisting in the coping process. These factors are proposed to relate to psychological states in two ways. They directly contribute to psychological well-being and they moderate the effects of stressors on well-being outcomes. Theory and research support the role of dispositional characteristics (Antonovsky, 1979; Kobasa, 1979; Rabkin & Struening, 1976) and perceived social support (Cohen & Wills, 1985; Schaefer, Coyne, & Lazarus, 1981) in influencing adaptational outcomes, both directly and indirectly by buffering against stress.

The current model further suggests that dispositional and social support factors moderate the impact of emotional states on physical health, after an emotional reaction has occurred. For example, a major loss will elicit an experience of emotional distress and grief for most people, but only a few will develop chronic hopelessness. In the current

framework, dispositional and social support factors are perceived as contributing to the resolution of emotional states, by influencing a person's perception of their options and assisting adaptation. This process is comparable to the role of secondary appraisal in the theoretical framework of coping developed by Lazarus (Lararus & Folkman, 1984). It is likely that acute and chronic emotional responses have different consequences for physical health (Lazarus & Folkman, 1984).

The hypothesis that a person's disposition has an effect on his or her social relationships and perception of feeling supported is also included in the current model. Research findings suggest that people who are cheerful, outgoing, high in self-esteem and self-confidence tend to acquire an extensive support network, in contrast to people who are shy, inhibited, withdrawn and low in self-esteem, who tend to have an inadequate network (Jones, 1985; Newcomb, 1990).

Finally, the present model proposes that changes in physical health, particularly those related to worsening of MS, will have an effect on a person's social relationships and perceptions of feeling supported. People with chronic illness involving increasing physical disability, often require support from others, particularly during difficult times in their illness (Melamed & Brenner, 1990). Research on the experiences of people with MS strongly suggests that personal relationships change as a result of the disease (Eklund & MacDonald, 1991; Robinson, 1988). (See Note 1, p. 301).

RESEARCH AIMS, ANALYTIC STRATEGIES AND THEIR RATIONALE

Given the very complex nature of the illness process in multiple sclerosis and thus of the theoretical model that reflects this intricacy, it is an advantage to examine the data from a number of different positions. The aims of the present study will be explained in the context of the four analytic approaches utilised.

The first aim of the present study is to test hypotheses regarding associations between variables in the model at a single point in time, in the largest group of patients available under the circumstances. This analytic approach, based on cross-sectional data,

employed conventional between-subject analyses to examine variable levels, variability, and correlations at an aggregate level. The findings from these analyses offer a basis of comparison for previous studies on psychosocial aspects of MS, which have almost exclusively employed cross-sectional designs and therefore between-subject analytic approaches.

The second aim of this study is to test hypotheses regarding associations among variables in the model as they change over time. This approach, based on longitudinal data over a seven month period, utilised within-subject analysis on a small subsample of twelve participants, to test variable relations at the aggregate level. The unit of analysis was the individual's score at a particular time point, thus the effective sample size was 7 x 12 = 84. The findings provided summary patterns of changing variable associations over a seven month period.

The third aim of the present study is to examine variable relationships in the model at the individual case level, as they change over time, taking into account some contextual information about the subjects. A descriptive approach was used to examine variables as they changed singly and jointly, and individual patterns in the data were compared with aggregate findings. It has been argued that when data is examined exclusively at the aggregate level important information about the person may be lost (Valsiner, 1986).

> Knowledge about how individual subjects function as systems cannot be generated by mere summation of the data about individual cases with the aim of finding the average or typical among a sample of systems. Instead,the functioning of the system should be explained first in the individual case. (Valsiner, p. 393)

In the context of chronic illness, valuable information can be obtained about how individuals experience their illness. This has implications for treatment interventions. Health professionals may be more proficient at offering treatment and advice if they understand their patient's everyday reality (Gerhardt, 1990).

The fourth aim is to examine the variable associations in relation to an acute change in physical status in one individual. The final approach, based on the longitudinal data,

was descriptive and involved an in depth illustration of the MS illness process against a fuller contextual background. The case study characterizes the experiences of a woman immediately prior to and following a major exacerbation of the disease.

CHAPTER 4

METHOD

This study consisted of a cross-sectional phase, followed by a longitudinal phase. The participants in the longitudinal phase of the study were a subgroup of the cross-sectional sample. Procedures for the two phases of the study were different, and these are discussed in detail below. Measures used in the cross-sectional phase of the study were repeated in the longitudinal phase of the study. However, some additional measures were also included in the longitudinal phase, to expand assessment of changes in physical status.

PARTICIPANTS

Participants were a convenience sample of women and men over the age of 18, residing in the Manawatu region of the North Island of New Zealand, who had been diagnosed as having multiple sclerosis (MS). Initial contact with participants was made through the Manawatu Multiple Sclerosis Society. The Vice President of the local branch of the Society mailed each member (with the exception of those deemed mentally incompetent) a letter inviting them to participate in this project (see Appendix A). A letter from the researcher accompanied the Society's letter, describing the study and the commitment it would involve for the participant (see Appendix A). Individuals who were interested returned the form at the bottom of the letter, providing their name and telephone number. Of the 70 letters mailed, 49 people responded (70%). The researcher then telephoned each person, answered any questions about the study, informed her or him about the consent form to be signed (see Appendix B), and set an appointment for an interview.

One criterion for exclusion from this study was severe cognitive impairment, which is an occasional feature of MS. People with this type of impairment would be unable to understand the questions asked and make appropriate responses. To assess this during the interview, participants were screened using the Mini-Mental State (Folstein &

Folstein, 1975). Details about this measure and respondents' scores are given in the measures section. All participants in this study had acceptable scores. This was reassuring but not surprising in light of the self-selection process, telephone contact with the researcher prior to the interview, and the Society's decision to send letters only to members that they viewed as mentally competent.

Eventually 45 interviews were successfully completed in the cross-sectional phase of the study. One interview had to be prematurely terminated because the participant appeared to be emotionally unstable. The other three interviews did not eventuate for various reasons: in one case the person suffered an accident, in another case the person could not be located, and in the third case, a telephone conversation suggested that the person was experiencing confusion and possible dementia.

Participants for the longitudinal phase of the study were obtained by inviting participants in the cross-sectional phase of the study to continue their involvement (see Appendix A). As in the initial contact, those people who were interested returned the form provided. They were asked to sign another consent form (see Appendix B) which was relevant to this part of the study. Only people residing in the city were invited to continue in the study because all subsequent interviews were to be conducted at the Rehabilitation Unit of the local hospital. This phase of the study was limited to 12 people because of practical considerations. The target level of 12 volunteers was reached after extending invitations to 19 participants, a 63% acceptance rate. No additional selection criteria, except place of residence, was used in this phase of the study. Participants were not systematically sampled from the cross-sectional group.

Demographic information

The cross-sectional sample comprised 32 women and 13 men, who ranged in age from 24 to 75 years (mean = 51 years). Demographic information is presented in detail in Table 1. The majority were married (62%), and only 10 people (24%) lived alone. All participants were of European/Pakeha ethnic background, and the vast majority were currently unemployed (82%).

Socio-economic levels, based on the six categories of the Elley-Irving Socio-Economic Indices (Buttle, 1980) indicated that most participants (65%) previously held middle level (3-4) positions. These typically represent semi-technical, clerical or sales related jobs requiring some degree of training. Participants ages at the time they were diagnosed with MS varied greatly, ranging from 17 to 69 years (mean = 39 years). Some of the participants (28%) had other chronic health conditions, but these were always secondary to their MS in terms of medical importance. Approximately half of the respondents lived in the city, and the other half lived in outlying areas.

The longitudinal sample, which is a subgroup of the larger sample, consisted of 8 women and 4 men. They ranged in age from 36 to 68 years (mean = 54). Six of the people in this group were married, two were widowed, and three were divorced. Out of the unmarried participants three lived alone, one lived with a sister, one lived with a teenaged child, and one lived at the hospital. At the onset of the study all participants were unemployed, however, one person was employed intermittently throughout the research period. Their socio-economic status, based on previous occupations, paralleled that of the larger sample. Participants' ages at time of the MS diagnosis ranged from 27 to 62 years (mean = 45 years). Three people (25%) had other chronic health conditions, secondary to their MS.

Table 1. *Demographic Information about Participants*

	Cross-Sectional Sample		Longitudinal Subgroup	
Variable	*N*	%	*N*	%
SEX				
Female	32	71.1	8	66.7
Male	13	28.9	4	33.3
AGE				
20-29	2	4.4	0	0.0
30-39	8	17.8	2	16.7
40-49	10	22.2	2	16.7
50-59	10	22.2	3	25.0
60-69	12	26.6	5	41.7
70-79	3	6.7	0	0.0
AGE AT DIAGNOSIS				
15-19	1	2.2	0	0.0
20-29	12	26.7	1	8.3
30-39	12	26.7	3	25.0
40-49	8	17.7	1	8.3
50-59	10	22.3	6	50.0
60-69	2	4.4	1	8.3
MARITAL STATUS				
Married	28	62.2	6	50.0
Widowed	6	13.3	2	16.7
Divorced/Separated	9	20.0	4	33.3
Single	2	4.4	0	0.0
LIVING ARRANGEMENT (all that apply)				
With spouse	28	62.2	6	50.0
Alone	10	22.3	3	25.0
With dependent child	14	31.1	2	16.7
With adult child	6	13.3	2	16.7
With friend	2	4.4	0	0.0
With parent	1	2.2	0	0.0
Other	3	6.7	1	8.3

PROCEDURE

The cross-sectional phase of the study involved the participants in one structured interview which was conducted by the researcher at the participant's home. The questionnaire contained measures of social support, disposition, psychological well-being, stress, and physical health status as well as demographic information (see the following section and Appendix C). Answering these questions took approximately two hours. The researcher was often at participants' homes longer in order to establish rapport and because some individuals wanted to discuss personal issues.

The longitudinal phase of the study involved participants for an additional six months. For this group, psychological and physical data was collected monthly. The participants were asked to come to the Rehabilitation Unit of the local hospital once a month for six months. At each visit they were given a brief clinical examination by a specialist physician who was the Director of the Rehabilitation Unit. The physician had considerable experience with multiple sclerosis patients. During his examination of the patient, he completed standardized measures to assess impairment, disability and overall health change, as well as noting medications and other chronic health concerns (see Appendix C).

Afterwards, the participants met with the researcher who conducted a structured interview. The questionnaire, on each of the six occasions, contained the same measures of psychological well-being, stress, and health status that were included in the cross-sectional interview (see Appendix C). The entire process took people approximately two hours each month. Participants were reimbursed for their travel expenses.

An eighth structured interview was held with each participant at their home, within a few days of their last session at the Rehabilitation Unit. During that meeting, social support and dispositional measures, identical to those contained in the first questionnaire, were collected. Cognitive functioning was also reassessed to verify that substantial deterioration had not occurred during the seven month period. The meeting

was also used to facilitate a closure in the relationship between the researcher and the participants and to thank people for their assistance with the study.

The information in the eighth interview was gathered separately to avoid tiring the participants (see Appendix C). However, as the measures represented relatively stable constructs and were collected within a few days from the seventh interview, they were considered part of the seventh data collection for the purpose of analysis.

MEASURES

Careful consideration was given to selecting measures that have demonstrated satisfactory validity and reliability in prior research, and which would not be too taxing or distressing for the respondents. Several of the measures were revised or extended to make them more relevant to this study, and this will be discussed later in regard to each measure. Table 2 provides a summary of all of the variables that were assessed and the data collection times. The measures are provided in full in Appendix C.

Table 2. *Variables Assessed and Data Collection Times*

Constructs and Variables	Times Administered
DEMOGRAPHICS	
Age	1
Sex	1
Marital status	1
Live with whom	1
Ethnic group	1
Employment status	1
Occupation	1
Age at diagnosis	1
Other chronic health conditions	1
STRESSORS	
Hassles	1-7
Life events	1-7
DISPOSITION	
Meaning in life	1,7
Locus of control	1,7
Health locus of control	1,7
Optimism	1,7
SOCIAL SUPPORT	
Social support network	1,7
Social support satisfaction	1,7
PSYCHOLOGICAL WELL-BEING	
Hopelessness	1-7
Anxiety	1-7
Depression	1-7
Positive affect	1-7
Negative affect	1-7
Life satisfaction	1-7
PHYSICAL HEALTH STATUS	
Disability (ADL)	1-7
Symptom frequency	1-7
Symptom intensity	1-7
Self-rated health change	1-7
Sexual satisfaction	1,7
Cognitive function	1,7
Disability (FIM)*	2-7
Impairment status*	2-7
Neurologic dysfunction*	2-7
Other-rated health change*	2-7

Time 1 refers to the cross-sectional phase of the study.
* Measures collected at physical examination.
FIM-Functional Independence Measure; ADL-Activities of Daily Living

PSYCHOSOCIAL MEASURES

Stressors

Hassles

Minor stressors were measured using the revised Hassles Scale (DeLongis, Folkman, & Lazarus, 1988) which is a shortened version of the original 117 item scale (Kanner et al., 1981). The measure is a checklist that asks respondents to rate 53 potential hassles on a 4-point scale. The items reflect a variety of everyday concerns: work, family, social activities, environment, practical consideration, finances, and health. The scale was scored for the cumulated severity of hassles (Kanner et al., 1981, p. 9). Previous research has found the original scale to be contextually sensitive, and effective in predicting adaptational outcomes (Chamberlain & Zika, 1990).

Life events

To provide contextual information about any major changes in a respondent's life, an additional question was included. In contrast to the Hassles Measure, a checklist format was not used. Rather, participants were asked to name major events that they had experienced during the last month and to rate the extent to which each had influenced their life, on a 4-point scale. It was appropriate to include this measure because prior research has found only a modest association between daily hassles and major life events, suggesting that the two variables provide different measures of stressors (Chamberlain & Zika, 1990).

Disposition

Meaning in life

A revised version of the Purpose in Life Test (PIL) (Crumbaugh, 1968) was included to assess the extent to which respondents experience a sense of meaning and purpose.

The original 20 item scale has been reported to have split-half reliabilities in excess of .90 (Crumbaugh, 1968; Crumbaugh & Maholick, 1964; Reker 1977), with test-retest coefficients of .83 (Meier & Edwards, 1974) and .68 (Reker, 1977). However, the scale has been criticised on validity grounds for being confounded with other concepts, in particular life satisfaction (Dufton & Perlman, 1986), depression (Dyck, 1987; Yalom, 1980), and control (Chamberlain & Zika, 1988; Dyck, 1987). Although meaning in life may conceptually overlap with other concepts, neither factor analysis (Chamberlain & Zika, 1988; Dufton & Perlman, 1986; Reker & Cousins, 1979) nor attempts to assess face validity (Yalom, 1980) have fully resolved the issue. Researchers have proposed different sets of items to most clearly define the pure meaning dimension. This is complicated by the way in which meaning is defined and by fairly arbitrary factor labelling.

In the present study, selection of items was guided by both the consideration of the confounding issue and the most appropriate definition of meaning for this sample. Items were eliminated which appeared to most clearly contain aspects of positive affect, negative affect, depression and control, as these concepts were assessed with different measures in the present study. Five life satisfaction/affect items (1,2,5,9,19) and two control items (14, 18) were dropped. Thus all items noted by Dufton and Perlman (1986) as most clearly representing life purpose were retained, and five of the seven items they suggested represented life satisfaction were eliminated. In addition the two items found by Chamberlain and Zika (1988) to relate to control were dropped. Respondents rated the remaining 13 items on a 7-point scale, ranging from *high purpose* to *low purpose*.

In the cross-sectional sample, the 13 item measure had an acceptable alpha reliability of .78, however, item seven correlated negatively with the other items and reduced the overall alpha. The content of this item related to future retirement and appeared inappropriate for this sample, the majority of whom were permanently unemployed due to their health. Therefore, item seven was dropped, and the remaining 12 items, with an alpha reliability of .81, were used in subsequent analyses.

Locus of control

Perceived control was measured using the James Internal-External Locus of Control Scale - short form (James, 1957 cited in Robinson & Shaver, 1973). The scale assesses internal-external locus of control as defined by Rotter (1966). The original 30 item scale is reported to have split-half reliabilities ranging from .84 to .96 and test-retest reliabilities ranging from .71 (one year) to .86 (3 months)(Robinson & Shaver, 1973). The scale has a simple factor structure and a substantial number of items which are not gender specific. The short form of the measure, consisting of 11 items, arises from a factor analysis (MacDonald & Tseng, 1971, cited in Robinson & Shaver, 1973).
It has been used successfully in New Zealand and has demonstrated high internal consistency with samples of young mothers (alpha = .84) and the elderly (alpha = .88) (Zika & Chamberlain, 1988) as well as with unemployed people (alpha = .77 & .80) (Hesketh, 1982).

The shortened scale was appropriate for the present study where one of the guiding criteria for selection was that minimal time and energy be needed to answer questions. Respondents rated the 11 items on a 4-point scale, ranging from *strongly agree* to *strongly disagree*. The alpha reliability was acceptable at .82.

Health locus of control

A sub-scale of the Multi-Dimensional Locus of Control Scale (MHLC) (Wallston, Wallston, & DeVellis, 1978) was included to assess the degree of control people experience in relation to their health. The MHLC is a multidimensional measure which assesses three dimensions of locus of control health beliefs: internality (IHLC), powerful others (PHLC) and chance (CHLC). The scales correlate in appropriate ways with each other and are also conceptually associated with Levenson's I, P & C (internal, powerful others & chance) Scales (Wallston et al., 1978). Alpha reliabilities for the six item scales have been reported in the range of .67 to .77 (Wallston et al., 1978).

In the present study, only one of the three scales provided by the measure, the IHLC

(internal health locus of control) scale was included. Wallston et al. (1978) asserted that using a single scale is entirely appropriate, and that this decision should be based on the sample, the health behaviour of interest, and the time available. In this case, the focus was on how much control people with MS believed they had over their health, and the IHLC scale appears to provide the best assessment of this. The six items were rated on a 5-point scale from *strongly agree* to *strongly disagree*. The alpha reliability was .81, indicating strong internal consistency among the items.

Optimism

The Life Orientation Test (LOT) (Scheier & Carver, 1985) was used to assess dispositional optimism, that is, the degree to which people expect good things to happen to them. The eight item scale (with four filler items removed), was reported to have an acceptable level of internal consistency (alpha = .76), and to be reasonably stable over a 4-week interval (test-retest correlation = .79). It has also been shown to possess an adequate level of convergent and discriminant validity (Scheier & Carver, 1985). Although the measure has been described as essentially unidimensional (Scheier & Carver, 1985), recent evidence suggests that the measure is comprised of two distinct dimensions, optimism and pessimism (Schwarzer, 1994). This finding was reported subsequent to the planning of the present study, and therefore optimism was regarded as unidimensional.

For the present study, the wording of some items was modified slightly, by removing the time dimension (e.g. usually, always, hardly-ever, etc.) To increase the relevance of the content, four additional items were included to assess people's optimism in regard to their health. The focus was on the person's expectation that in the future he or she can look forward to good health, or alternatively, to poor health.

Respondents rated the extent to which they agreed with the twelve statements, on a 4-point scale. The internal consistency of the 12 items was lower than expected (alpha = .54). This could be partly attributed to item 1 which was negatively correlated with the other items and reduced the overall alpha. The content of this item relating to "in

uncertain times" may be difficult for people with MS to interpret because as a consequence of their illness, life is constantly uncertain. Taking this into account, item 1 was deleted, and the overall alpha reliability increased to .61. The set of health items, which is not part of the LOT, did not reduce the overall alpha.

Social support

Perceived social support

Social support was assessed by a brief form of the Social Support Questionnaire (SSQ) (Siegert, Patten, & Walkey, 1987). This instrument, a shortened version of the original 27 item SSQ (Sarason, Levine, Basham, & Sarason, 1983), provides scores on both perceived network size and satisfaction with perceived support. The measure comprises 12 items from the parent scale. The shortened scale, which was modified and validated using New Zealand samples, has demonstrated high internal reliability, as well as acceptable convergent and discriminative validity (Siegert et al., 1987). In the present study participants had limited time and energy, and a specific health condition which required further modifications to the scale. First, the shortened SSQ was again reduced using a New Zealand data set of 174 people who had completed the 12 item SSQ (Dowall, 1989). Items were excluded if they correlated at least .60 with another item, had substantial repetitive content, and internal consistency of the overall scale remained high when the item was dropped. Accordingly, four items (7,9,13,19) were deleted. Second, in order to assess aspects of social support which are specifically relevant to people who have MS, two additional items were included. One item focused on emotional support and the other item on practical support.

Respondents answered each of the remaining eight SSQ items and the two items focusing on MS twice; firstly, to identify people who are perceived as available to provide support, and secondly, to rate their level of satisfaction. The modified scale demonstrated high alpha reliability for both perceived support network (.83) and support satisfaction (.88).

Sexual satisfaction

Sexual satisfaction was evaluated in terms of respondents' satisfaction with the emotional, physical and sexual aspects of their relationship. The components and corresponding definitions were taken from a study (McLellan et al., 1989) that assessed the effects of MS on intimate relationships. This measure does not assess symptoms of sexual dysfunction, but provides an indication of which aspects of intimacy are satisfactory or problematic.

The sexual satisfaction measure could only be completed by participants who had a partner, approximately one third of the cross-sectional sample, and one half of the longitudinal group. A substantial drop in the *N* for this measure made it unsuitable for analyses using correlational statistics. In the light of this, and because sexual satisfaction was not a core variable, a decision was made to exclude the data from the analyses.

Psychological well-being

Hopelessness

Hopelessness was assessed using a subset of items from the Hopelessness Scale (HS) (Beck, Weissman, Lester, & Trexler, 1974). The measure comprises 20 statements that reflect different facets of negative attitudes towards the future. The scale has demonstrated high internal consistency (KR-20 = .93), and has well established concurrent and construct validity. A factor analysis of the scale suggested that it is comprised of separate affective, motivational and cognitive components (Beck et al., 1974).

In the present study, only the motivational component (eight items) of the HS was included, as the giving-up attitude was of particular interest to this study. The statements were answered in a true/false format. The shortened measure retained acceptable internal consistency (alpha = .79).

Depression and anxiety

Depression and anxiety were measured using the depression and anxiety lower-order scales of the Mental Health Inventory (MHI) (Viet & Ware, 1983). The MHI is based on a hierarchical factor model of mental health comprised of a general mental health factor, two higher-order factors labelled psychological distress and psychological well-being, and five lower-order factors. The MHI contains 38 items and can be scored at the general, higher-order or lower-order level. Internal consistency estimates range from .92 to .96 for the higher-order and general factors, and at .83 to .91 for the lower-order factors (Viet & Ware, 1983).

In the present study only the lower-order anxiety and depression scales were used. Both scales are appropriate for use with a sample of MS people because they do not have a strong somatic emphasis. The anxiety scale is comprised of 9 items which reflect clinical anxiety symptoms, the vast majority of which are psychological rather than somatic. The one exceptional item, focusing on physical aspects of anxiety (e.g. hands shaking), was deleted. The depression scale comprises four items that assess depressed mood, but does not measure other aspects of depression (ie. anhedonia, psychomotor retardation, somatic symptoms).

Participants rated the eight anxiety items and the four depression items on either a 5 or 6-point response scale, depending on the item. Internal consistency reliability was acceptable for both anxiety (.86) and depression (.84).

Positive and negative affect

To assess general affective states the Positive and Negative Affect Schedule (PANAS) (Watson et al., 1988) was used. "...Positive Affect (PA) reflects the extent to which a person feels enthusiastic, active and alert. ...In contrast, Negative Affect (NA) is a general dimension of subjective distress and unpleasurable engagement that subsumes a variety of aversive mood states..."(Watson et al., 1988, p. 1063). The measure has been shown to have high alpha reliabilities for both scales (PA = .86 to .90, NA = .84

to .87), to encompass two largely uncorrelated affect dimensions, and to have appropriate stability across time. The scale is also reported to correlate with a number of related constructs in meaningful ways, demonstrating strong construct validity (Watson et al., 1988). It is of particular interest to the present study, that intraindividual analyses have confirmed that the scales are sensitive to changing circumstances over short time periods (Watson et al., 1988).

The PANAS is comprised of 20 adjectives (10 positive, 10 negative) that were rated on a 5-point scale ranging from *very slightly* or *not at all* (1) to *extremely* (5). Alpha reliabilities were acceptable, at .80 for PA and .88 for NA.

Life satisfaction

Andrews and Withey's (1976) global measure, Life 3, was used to assess global life satisfaction. Andrews and Withey estimate Life 3 to have a validity coefficient of .8 (p. 188) and a test-retest reliability of .7 (p. 192). Life 3 is a single item measure which respondents answer twice, once towards the beginning of the interview, and again toward the end of the interview. A score is derived by summing the two responses.

Participants rated this item on a 1 to 7, delighted-terrible scale. The correlation, based on the two responses given in the interview, was .85.

PHYSICAL HEALTH STATUS MEASURES

Disability (ADL)

The Barthel Index (Mahoney & Barthel, 1965) was included to assess a person's level of disability. The measure was developed for use with the chronically ill, to allow medical personnel to assess patients' activities of daily living (ADL) before, during and after treatment. The 10 activities assessed by the index are: feeding, grooming, dressing, chair/bed transfer, bladder, bowels, toilet, mobility, stairs, and bathing. The index has demonstrated high inter-rater reliability as well as proving useful as a

predictor of progress in rehabilitation (Granger, Dewis, Peters, Sherwood, & Barrett, 1979). When compared to other ADL indices in the evaluation of stroke patients, it has been found to have distinct advantages (Gresham, Phillips, & Labi, 1980).

In the present study, the index was slightly modified to use as a self-completion measure, requiring some minor wording and scoring changes. Although the simplicity of the index made it feasible as a self-report measure, the instrument is not normally used as such, and therefore scores may not be comparable to those from prior research. Participants assessed their ability in each of the 10 areas using straightforward criteria (e.g. independent, needs help, dependent). The measure was scored to provide an overall ability indicator, by summing all 10 areas.

Physical symptoms

Common physical symptoms of multiple sclerosis were assessed both for frequency and intensity. "The chief characteristics of the symptoms of MS are multiplicity and the tendency to vary in nature and severity with the passage of time" (Peyser & Poser, 1986, p. 368). Symptoms are wide ranging, however it was not feasible to assess all possible symptoms because of time constraints. Therefore, twelve symptoms were included that have been commonly reported in the MS literature (e.g. Lafferty, McKay, Matthews, Sipeli, & Trotman, 1988; Scheinberg & Smith, 1987). Of these, eleven would be considered primary symptoms, resulting directly from an area of demyelination. The other one (pressure sores) would be considered a secondary symptom, arising from the complication of a primary symptom (Scheinberg & Smith, 1987).

Respondents rated each symptom twice. First, they indicated how often they had experienced a particular symptom in the past month, on a 5-point scale ranging from *never* to *constantly*. Second, they assessed the degree of intensity for any symptom that they had experienced during the past month, on a 10-point scale ranging from *not at all* to *extremely*. A total score was derived for symptom frequency by summing the numbers of each response. A total score for symptom intensity was calculated in the

same manner.

Self-rated health change

A self-rated health measure was included to assess whether participants perceived their health as being the same, worse or better than the previous month. This single item measure used a 5-point response format ranging from (1) *very much better than last month* to (5) *very much worse than last month*. Self-assessment of health has been found to be a useful indicator of actual health status (Maddox & Douglass, 1973) and to correlate significantly with psychophysiological symptoms (Garrity, Somes, & Marx, 1978). Similar single item health measures have been used successfully in previous research (Palmore & Luikart, 1972).

Physical examination measures

Additional health status measures were collected for longitudinal participants by a physician during monthly physical examinations. In an attempt to increase consistency and accuracy, as well as to optimise the physician's time, information obtained during the previous month was used as a reference point. Although this practice may be viewed as biasing the assessments, the physician retains an impression of the person from the previous examination regardless of whether previous notes are consulted. Involving a different physician at each data collection point was not practicable.

Disability (FIM)

Participants' level of disability was assessed using the Functional Independence Measure (FIM) Granger, Hamilton, Keith, Zielezny, & Sherwin, 1986). The FIM is utilised by medical practitioners to assess deficits, capabilities and assets of disabled patients. It focuses on a range of abilities: self care, sphincter control, mobility, locomotion, communication, and social cognition. FIM is a relatively new measure, developed by a task force after an extensive review of 36 available assessment instruments. Initial efforts to establish content validity and inter-rater reliability have been promising

(Granger, Cotter, Hamilton, Fiedler, & Hens, 1990). A recent study, which compared the FIM with other similar measures, found it to be the strongest tool in the functional assessment of people with MS (Granger et al., 1990).

An advantage of using this measure in the present study is the ease of administration. Trained clinicians can complete the FIM in an average of 11 minutes (Granger et al., 1986). In line with very specific assessment criteria (Data Management Service of the Uniform Data System for Medical Rehabilitation, 1987), the physician rated participants on 18 items using a 7-point scale. To create a total score, the item scores were summed, allowing a minimum score of 18 and a maximum score of 126. Although one of the abilities (social cognition) in the FIM does not depend on physical function, its exclusion would have jeopardised the measure's validity.

Impairment and neurologic dysfunction

The Kurtzke (1965) Disability Status Scale and Functional System Scales were used to assess the person's overall level of impairment and neurological deficit due to MS. This instrument, which is a revision of the original 1955 Kurtzke Status Scale, is commonly used by physicians to assess the activity of MS, to document change in the condition, and to assess treatment effects (Kurtzke, 1965). The Disability Status Scale (DSS) is comprised of eleven descriptive levels of impairment, ranging from 0 *normal neurologic examination* to 10 *death due to multiple sclerosis*. Research using the Disability Scale with MS patients has demonstrated a normal bell-shaped frequency curve (Kurtzke, 1965). Although a more recent version of this instrument is available, with an expanded scoring system (EDSS) (Kurtzke, 1983), the physician collecting this information had previous experience assessing patients with the DSS, giving him a strong preference for using it in the present study.

The Functional System Scales are comprised of descriptive levels of dysfunction, and are graded 0 to 5 or 0 to 6. The functional systems examined were: pyramidal, cerebellar, brainstem, sensory, bowel and bladder, and visual. Research has indicated that each functional system has varying degrees of involvement with MS, and percentage

of involvement ranges from 80% to 16% (Kurtzke, 1970). Mental functions were not examined in order to avoid problems of inflated correlations between physical and psychological factors. In previous research mental function demonstrated the weakest involvement with MS, showing only 5% of people dysfunctional in this area (Kurtzke, 1970). The other functions category was also not assessed in order to provide uniformity in the data. The physician used the usual rating criteria and assigned a number for impairment level as well as for each functional system. A total neurologic dysfunction score was derived by summing the scores assigned to the six functional systems. Kurtzke (1984) does not advocate summing the scores to create an overall measure for several reasons. Firstly, the sum tends to plateau before the theoretical maximum score; secondly, the scales have differing frequency configurations; thirdly, patients can improve in one area but worsen in another; and fourthly, the scales are considered to be ordinal. In terms of medical assessments for rehabilitation or treatment interventions these are compelling arguments. However, none of Kurtzke's arguments were of particular concern in the context of the present study which required an overall measure of neurologic dysfunction, and was not interested in specific areas of impairment. Further, on statistical grounds, using a single measure was preferable.

Other-rated health change

The health change measure that was used for self-assessment was also included to provide an *other* rated health change assessment. The physician made a determination about whether the person's health was the same, better, or worse than the previous month. He rated their overall health change (taking into account the activity of their MS) on a 1 to 5 scale. An assessment was not made during the first examination because there was not a reference point on which to base it.

SCREENING MEASURE

Cognitive function

In the present study it was unnecessary to examine cognitive function in depth, as this

factor was not represented in the theoretical model. However, as cognitive impairment is a feature of MS for certain people, it was important to screen out participants with serious cognitive impairment, to avoid introducing random error into the data. Although research supports the notion that some people with MS have cognitive impairment, results concerning the prevalence and severity of the disturbance have been equivocal (see Peyser & Poser, 1986 for review). Participation in this study required the ability to understand the questions and answer them in meaningful ways.

As a screening measure, the Mini-Mental State (MMS) (Folstein & Folstein, 1975) was included. The scale was devised to provide a simple and brief measure of cognitive aspects of mental functions. As a clinical tool, it has been found to distinguish between different psychiatric groups and normal groups. It also has well established concurrent validity. Test-retest reliability over a 24 hour period has been reported in the range of .83 to .88 (Folstein & Folstein, 1975). In prior research the MMS has been used successfully with MS patients (Rabins et al., 1986), and had distinct advantages for use in the current study. Firstly, it is exceedingly brief and straightforward to administer, taking around 5 to 10 minutes. Secondly, it assesses a variety of cognitive functions including orientation, memory, attention, recognition and naming of objects, and ability to follow instructions.

In the present study many participants had visual problems and/or restriction of mobility which made writing difficult. The MMS therefore required a few modifications: 1) the researcher read commands aloud that would normally be read by respondents, 2) respondents created a spontaneous sentence verbally instead of in writing, and 3) the item requiring respondents to draw a complex polygon was deleted. A total score was derived by summing all items, with a possible maximum of 28 points instead of the usual 30 points (see Appendix C).

Prior research has found that groups of senile patients achieved MMS scores in the 9.6 to 12.2 range. In contrast, control groups comprised of normal elderly people and younger patients with functional psychiatric disorders, scored in the 24.6 to 27.6 range (Lezak, 1983). Scores in the present study ranged between 21 and 28 points in the

cross-sectional group (M = 26.8; SD = 1.56), which indicates an absence of serious cognitive dysfunction. In the longitudinal subsample, cognitive functioning did not deteriorate over the seven month period (Time 1: $M = 25.75$, $SD = 1.71$; Time 7: $M = 26.25$, $SD = 1.86$).

DATA ANALYSIS

All cross-sectional questionnaires were completed by the researcher in a structured interview format; consequently there was no missing data. During the longitudinal phase of data collection, participant compliance rate was 100% for keeping appointments, thus complete monthly data was available for every subject.

The conceptual appropriateness of using particular analysis approaches in the current study was discussed in chapter 3. As noted, four different approaches were used in analyzing the data. The first two methods used statistics at the aggregate level, and the latter two methods used descriptive accounts of changes in scores at the individual level. The findings are presented in four separate results chapters, each with a distinctive focus. In this section, some statistical issues related to chapters 5 and 6 will be discussed.

In chapter 5, the analyses of data collected during the cross-sectional phase of the study are presented. These analyses provided a picture of variable associations in the theoretical model, using between-subject variability, at a single point in time.

Bivariate correlations were examined using two-tailed tests of significance. Hypotheses based on specific associations between variables were tested using hierarchical and standard multiple regression analysis. The sample size of 45 was questionable for using multiple regression analysis (Tabachnick & Fidell, 1989), but unavoidable in the context of this study. It was impossible to compile a larger sample, as every referral within the region was investigated. Due to the relatively small sample size, multivariate techniques that are capable of analyzing all variable relationships as a whole (ie. path analysis, LISREL) were inadvisable.

A number of factors contributed to the decision to use multiple regression analysis. Firstly, overall, the patterns of correlations between variables appeared sensible and in line with previous research findings. Secondly, when testing relations in a complex model, it is important to be able to control the effects of several variables simultaneously in order to eliminate possible confounding associations. Thirdly, early exploratory analyses revealed that, despite the small *N*, some significant relations between variables were evident. Therefore, on balance multiple regression analysis seemed an appropriate choice. However, because of the small sample size, it is important to take a cautious approach when interpreting the results.

Some of the hypotheses involved the examination of moderating effects. All scores were converted to deviation scores around group means (centred), with the exception of life events which was a dichotomous split, prior to forming multiplicative terms to represent interaction effects. This avoids high correlations between product terms and component parts of the term (Jaccard, Turrisi, & Wan, 1990).

Moderating effects were analysed using hierarchical regressions, where all main effects were entered together, on step 1 and all the two-way interaction effects were entered in a block, on step 2. In these analyses, the usual significance level of .05 was adopted. In total, numerous regressions were run, which can be viewed as optimising the chance of finding significant effects. However, each analysis was based on a planned research question and was necessary to achieve conceptual understanding of the model. Though some outcome variables were statistically related, it was important for conceptual clarity to consider them separately. (See Note 2, p. 301).

In chapter 6, analyses of the data obtained during the longitudinal phase of the research are presented. A major shift in focus occurs in this chapter, from examining between-subject variability in the data, to within-subject variability. The emphasis is on changes in variables as they relate to changes in other variables, over time. The only relation in the model that does not involve change, the disposition - social support relation, was necessary to include for conceptual completeness.

The analyses presented in this chapter, treat scores as episodes, creating in effect an *N* of 84 (7 data collections x 12 subjects). Scores for the change variables, stressors, psychological well-being, and health status, were converted to deviation scores, around within-person means, following the procedure recommended by Bolger, DeLongis, Kessler, & Schilling (1989). This eliminated between-subject variability and specific time points, but maintained the time structure of the data. Scores for the unchanging factors, disposition and social support, collected on two occasions only, were averaged. The dispositional measures were regarded conceptually as being relatively stable, and correlations of these variables, collected approximately six months apart, generally support this assumption, although optimism unexpectedly demonstrated only moderate stability (locus of control, $r = .90$; health locus of control, $r = .73$; meaning in life, $r = .83$; optimism, $r = .48$).

Due to the time it takes to complete social support measures, it was not possible to measure social support on more than two occasions. Therefore, a score representing an average level of social support over six months was considered appropriate for use in this study. Correlations of the social support variables, obtained at time one and time seven, suggest that they are relatively stable (social support network, $r = .59$; social support satisfaction, $r = .74$).

As in the cross-sectional analyses, Pearson correlations, using 2-tailed tests of significance were used. Correlations for stressor, psychological well-being, and physical health status variables, were within-subject estimates.

The longitudinal data was analysed using within-subject hierarchical and standard multiple regression. Hypotheses were tested involving main effects and two-way interaction effects. As noted earlier, scores from serial measures were converted to deviation scores, around within-subject means. It was necessary, however, to transform averaged scores to deviation scores (around group means) prior to forming multiplicative terms. In the hierarchical regressions, all main effects were entered together on step 1, and all two-way interaction effects were entered in a block, on step 2. The usual significance level of .05 was adopted in these analyses. In a previous study examining

serial within-subject scores, the calculation of *p*-values was based on the number of subjects, rather than the number of episodes, to insure that findings could be generalised to other people (Omodei & Wearing, 1990). However this was not done in the present study, as the objective was seen as generalizing to the population of episodes for this group of subjects. Numerous regressions were run based on planned hypotheses and necessary for the conceptual understanding of the model. (See Note 3, p. 302).

ETHICAL CONSIDERATIONS

Ethical concerns focused on: informed consent, confidentiality, medical procedures, dependency issues, and psychological impact. A detailed account of these issues and the manner in which they were approached can be found in Appendix D. This research project was reviewed and approved by the Massey University Human Ethics Committee, the Palmerston North Hospital Research Committee and the Manawatu Multiple Sclerosis Society.

CHAPTER 5

CROSS-SECTIONAL RESULTS: EXAMINING RELATIONSHIPS IN THE MODEL

This chapter focuses on the results arising from the cross-sectional phase of the study. It begins with a description of the univariate characteristics of the data, including an examination of variable distributions. It then presents bivariate statistics and a discussion of the key bivariate relationships. The second half of the chapter presents a series of multiple regression analyses. Here, relations among the variables are examined in a more controlled fashion and interaction effects are considered. The regression findings are described in the present chapter and will be more fully interpreted in the Discussion and Conclusion chapter (chapter 9).

The cross-sectional between-subject analyses discussed in this chapter test hypotheses that concern associations between variables in the theoretical model at a particular point in time. This analytic approach allows levels of variables and between-subject variability to be examined in the largest sample possible under the circumstances. The findings offer a basis for comparison with most previous research focussed on the psychosocial correlates of MS, which have also been based on cross-sectional between-subject data.

UNIVARIATE CHARACTERISTICS

As discussed earlier, the theoretical model comprises five major constructs: stressors, disposition, social support, psychological well-being, and physical health status. A diagrammatic representation of the model is re-presented in Figure 2.

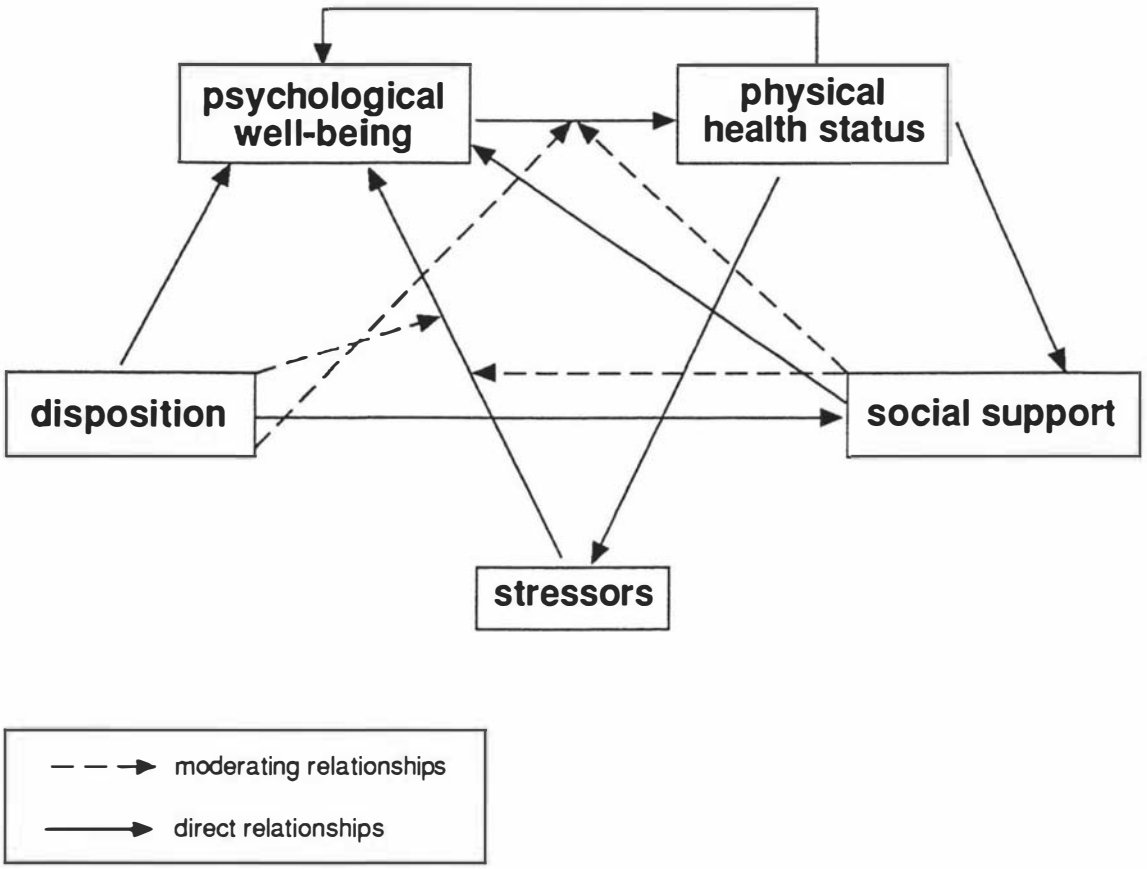


Figure 2. Model relating psychosocial and physical factors in multiple sclerosis.

Each construct is defined by a set of variables. The means and standard deviations obtained for each of the variables collected in the cross-sectional phase of the study are presented in Table 3. The majority of variable distributions did not depart substantially from normality, the notable exceptions being hassles, life events, social support satisfaction, hopelessness, and disability (ADL).

Table 3. *Means and Standard Deviations of Cross-sectional Variables (N = 45)*

Variables	*M*	*SD*
STRESSORS		
Hassles	20.82	13.56
Life events	1.76	1.88
DISPOSITION		
Meaning in life	62.58	10.39
Locus of control	17.91	4.33
Health locus of control	16.91	4.53
Optimism	37.27	4.46
SOCIAL SUPPORT		
Social support network	28.24	11.91
Social support satisfaction	53.62	6.78
PSYCHOLOGICAL WELL-BEING		
Hopelessness	9.24	1.63
Anxiety	20.47	6.78
Depression	10.16	3.49
Negative affect	20.38	8.41
Positive affect	32.29	6.65
Life satisfaction	9.76	2.00
PHYSICAL HEALTH STATUS		
Self-rated health change	3.00	.77
Disability (ADL)	25.22	3.07
Symptom frequency	34.22	7.42
Symptom intensity	39.40	19.60

Hassles were positively skewed, which indicates participants reported few minor stressors. Life events showed a similar but more severe pattern of positive skewness. Many participants had not experienced any recent major life events (40%), and therefore the measure has limited variability. Social support satisfaction was negatively skewed indicating strong satisfaction in quality of support received. Hopelessness had positive skewness, with few participants reporting feeling hopeless. Finally, disability (ADL)

showed negative skewness, suggesting that, in general, participants coped well with everyday tasks.

The three variables that demonstrated the most severe deviations from normality were life events, hopelessness and disability (ADL). Data transformation is recommended as a remedy for failures of normality when the transformed variables can be sensibly interpreted (Tabachnick & Fidell, 1989). In the case of life events, a dichotomous split of life events/no life events (60%/40%) is conceptually appropriate, and therefore was adopted. The pattern of the hopelessness and disability (ADL) distributions did not support a dichotomous or trichotomous split, and other types of transformations would produce variables that could not be easily interpreted. Therefore, these variables were not altered.

BIVARIATE ANALYSES

Pearson correlations were examined: firstly to consider the interrelation of the variables within each major construct represented in the theoretical model, and secondly, to establish a preliminary picture of the associations between the constructs prior to multivariate analysis. The following account focuses on the strength and direction of the variable relations rather than on their statistical significance. However, p values, based on a two-tailed test of significance, are given for information either in parentheses or in the appropriate table. In addition, a complete correlation matrix presenting the intercorrelations of all the variables can be found in Appendix E (Table E-1).

Interrelationships within constructs

The stressor variables of hassles and life events correlated at a low level (r = .24, ns), showing a slightly weaker relation than in previous findings (Chamberlain & Zika, 1990). Conceptually, hassles and life events capture two very different aspects of stressors; the former evaluating chronic everyday stressors, and the latter assessing infrequent major life changes. Therefore, a strong relation between the variables would not be expected. Further, the transformed dichotomous life events measure may have

contributed to the weaker correlation.

The intercorrelations of the dispositional variables, meaning in life, locus of control, health locus of control, and optimism, are given in Table 4. Optimism relates moderately with all other variables. Locus of control (external) and health locus of control (external) are inversely related to optimism and meaning in life. The extremely weak association between locus of control and health locus of control may be attributed to the inclusion of only one subscale (refer to methods) of health locus of control.

Table 4. *Intercorrelations of Dispositional Variables (N =45)*

Variables	LOC	HLOC	OPT
MIL	-.25	-.14	.39**
LOC	-	-.04	-.46**
HLOC		-	-.49**

** $p < .01$

Note. LOC-Locus of control, HLOC-Health locus of control, OPT-Optimism, MIL-Meaning in life

The social support variables of social support network and social support satisfaction correlate at a moderate level ($r = .46$, $p < .01$), in agreement with previous findings (Siegert et al., 1987). Conceptually, some degree of overlap between network size and satisfaction is logical because social support satisfaction depends on having a social support network available. However, the moderate association does support the theory that the two aspects of social support capture different experiences.

The intercorrelations of the psychological well-being variables (hopelessness, anxiety, depression, negative affect, positive affect, and life satisfaction) were considered next. The associations of the well-being variables are given in Table 5.

Table 5. *Intercorrelations of Psychological Well-being Variables (N = 45)*

Variables	ANX	DEP	NA	PA	LS
HP	.07	.09	-.11	-.23	-.64**
ANX	-	.72**	.76**	-.00	-.28
DEP		-	.60**	-.14	-.40**
NA			-	.19	-.24
PA				-	.21

** $p < .01$

Note. ANX-Anxiety, DEP-Depression, NA-Negative affect, PA-Positive affect, LS-Life satisfaction, HP-Hopelessness

The negative well-being variables (hopelessness, anxiety, depression and negative affect) are strongly associated with the exception of hopelessness. This may be a consequence of the distribution of hopelessness, which as mentioned previously is skewed towards the positive.

The two positive well-being variables (positive affect and life satisfaction) correlate at a low level, which is considerably weaker than found in previous research (Zika & Chamberlain, 1987; Zika & Chamberlain, 1992). However, this discrepancy may be due to the use of different measures to assess positive affect. On theoretical grounds, a strong relationship between the variables should not be expected, because positive affect reflects an emotional assessment of well-being in contrast to life satisfaction, which is a more cognitive based assessment (Chamberlain, 1988; Diener, 1984).

The positive and negative well-being variables are weakly related, with two exceptions. Hopelessness has a high inverse correlation with life satisfaction, and depression has a moderate inverse correlation with life satisfaction. Positive affect and negative affect are weakly correlated as expected, but do not demonstrate the inverse relation reported in previous findings (Watson et al., 1988). However, this inverse relation has been shown to vary according to the context in which the measure was used (Watson et al., 1988).

Table 6 displays the intercorrelations of the physical health status variables (self-rated health change, disability (ADL), symptom frequency and symptom intensity). Self-rated health change is essentially unrelated to the other health status variables. This finding is somewhat unexpected, but may be explained by the variable being an assessment of overall health in contrast to the other health variables, which relate specifically to multiple sclerosis. Disability (ADL) (scored to reflect ability) demonstrates, as expected, a strong inverse relation with both symptom frequency and symptom intensity. Symptom frequency and symptom intensity are very highly correlated.

Table 6. *Intercorrelations of Physical Health Status Variables (N = 45)*

Variables	DIS	SYMFR	SYMIN
SHC	-.04	.04	-.02
DIS	-	-.40**	-.51**
SYMFR		-	.80**

** $p < .01$

Note. DIS-Disability (ADL), SYMFR-Symptom Frequency, SYMIN-Symptom intensity, SHC-Self-rated health change

Overall, the variable intercorrelations within the constructs are in the direction and of the magnitude that is consistent with previous findings. Conceptually, the relations are sensible. These results are reassuring given that the sample comprises a relatively small group of people with multiple sclerosis who volunteered to participate in this study.

Associations between psychological well-being and other constructs

Psychological well-being, the main psychological focus of the model, is the only construct which was posited to relate to every other construct. Therefore, it was important as a preliminary step to examine the associations of each construct with well-being. Table 7 presents the correlations of the variables representing each major construct (stressors, disposition, social support, and physical health status) with the psychological well-being variables.

Table 7. *Correlations of Psychological Well-being Variables with Stressor, Dispositional, Social Support and Physical Health Status Variables (N = 45)*

Variables	HP	ANX	DEP	NA	PA	LS
HASS	-.12	.64**	.38*	.66**	.05	-.17
LE	-.13	.33*	.08	.29	.17	.11
MIL	-.32*	-.08	-.23	-.09	.39**	.56**
LOC	.38*	.18	.07	-.00	-.39**	-.39**
HLOC	.09	.14	.39**	.01	-.30*	-.22
OPT	-.56**	-.19	-.44**	-.04	.28	.65**
SSN	-.33*	-.11	-.16	.08	.44**	.30*
SSS	-.13	-.08	-.21	-.04	.35*	.29
SHC	-.05	.00	-.09	-.01	-.04	.04
DIS	.01	.16	.07	.07	-.06	-.03
SYMFR	.14	.09	-.01	.10	.05	-.22
SYMIN	.07	.15	.12	.25	.18	-.15

** $p < .01$, * $p < .05$

Note. HP-Hopelessness, ANX-Anxiety, DEP-Depression, NA-Negative affect, PA-Positive affect, LS-Life satisfaction, HASS-Hassles, LE-Life events, MIL-Meaning in life, LOC-Locus of control, HLOC-Health locus of control, OPT-Optimism, SSN-Social support network, SSS-Social support satisfaction, SHC-Self-rated health change, DIS-Disability (ADL), SYMFR-Symptom frequency, SYMIN-Symptom intensity

Hassles is strongly related to anxiety and negative affect, and moderately correlated with depression. Associations with the other well-being variables are weak. Life events has weak relations with each of the well-being variables. The magnitude of the associations are similar to those reported in previous studies (Chamberlain & Zika, 1990). The overall pattern indicates that, with the exception of the correlation between hopelessness and hassles, the stressor variables have a stronger relation with the negative well-being variables than with the positive ones. This agrees with previous findings, where hassles demonstrated stronger relations with negative well-being outcomes than with those that were positive (Zika & Chamberlain, 1987).

The dispositional variables show varying relations with well-being. Meaning in life relates at moderate levels to the positive well-being variables. It is generally weakly correlated with the negative well-being variables. Locus of control (external) is moderately associated with hopelessness, and has inverse moderate correlations with the positive well-being variables. It is weakly related, at best, to the other well-being variables. Health locus of control (external) is moderately associated with depression, and has a weak relation with other well-being variables. Optimism relates strongly to life satisfaction, and has moderate inverse associations with hopelessness and depression. It has weak relations with other well-being variables. The overall pattern of the dispositional variables with the well-being variables is mixed, although the direction of the correlations is consistent with conceptual expectations. It is noteworthy that some well-being variables which are highly correlated (e.g. anxiety and depression) relate at varying magnitudes to different dispositional variables. This indicates that well-being variables, which appear to be strongly related, are capturing different emotional experiences.

The two social support variables (social support network and social support satisfaction) relate to the well-being variables in similar ways. They are moderately related to positive affect, and have weak associations with other well-being variables.

Finally, the four physical health status variables demonstrate weak, or non-existent relations with all of the psychological well-being variables. This pattern of results clearly indicates that well-being and health status are unrelated in this sample.

To summarise, hassles show a strong relation with several of the well-being variables. Generally, the association between life events and well-being is weak. Each dispositional variable demonstrates a moderate relation to one or more well-being variables, with optimism showing the strongest associations. The social support variables demonstrate weak to moderate relations with the well-being variables. Finally, the associations between the health status variables and the well-being variables are weak at best.

Associations among physical health status, social support, stressors, and psychological well-being constructs

Turning to the relation of health status variables to social support and stressor variables, and the association between dispositional variables and social support variables, their correlations are displayed in Table 8.

Table 8. *Correlations of Social Support and Stressor Variables with Physical Health Status and Dispositional Variables (N = 45)*

Variables	SSN	SSS	HASS	LE
SHC	-.09	.05	.16	.12
DIS	.08	-.16	.13	.22
SYMFR	-.10	-.06	.14	-.07
SYMIN	-.04	.05	.31*	-.12
MIL	.35*	.52**	-.03	.13
LOC	-.36*	-.11	.35*	-.21
HLOC	.02	-.11	-.04	.12
OPT	.32*	.17	-.07	.12

** $p < .01$, * $p < .05$

Note. SSN-Social support network, SSS-Social support satisfaction, HASS-Hassles, LE-Life events, SHC-Self-rated health change, DIS-Disability (ADL), SYMFR-Symptom frequency, SYMIN-Symptom intensity, MIL-Meaning in life, LOC-Locus of control, HLOC-Health locus of control, OPT-Optimism

The health status variables have consistent weak associations with the social support variables. They also are weakly correlated with the stressor variables. The dispositional variables demonstrate weak to moderate relations with the social support variables.

MULTIPLE REGRESSION ANALYSES

To test the hypotheses arising from the theoretical model, multiple regression analysis,

using SPSS-PC REGRESSION, was used. The arguments for using this statistical technique, and the treatment of the data were explained earlier in the Method chapter. As noted, some of the hypotheses involved testing for moderating effects, and consequently, all measures were converted to deviation scores (centred) prior to forming multiplicative terms, with the exception of life events which is a dichotomous split. When interpreting the regressions, *t*-values will only be considered when the overall equation for the step (*F*-value) is significant.

An examination of residuals from the numerous multiple regression analyses which are presented in this chapter revealed only one outlier. This outlier was only mildly deviant and hence was ignored. Inspection of the plots of the residuals revealed that there were no marked departures from linearity or homoscedasticity.

Determinants of psychological well-being

To test the hypothesis that stressors, disposition, social support, and physical health status relate to psychological well-being, and that the association between stressors and psychological well-being is moderated by social support and disposition, a series of hierarchical multiple regression analyses was performed. The six well-being variables, in turn, were treated as dependent variables. To test for main effects, all stressor, disposition, social support, and health status variables, were entered on the first step. To test for moderating effects, the product terms of disposition x stressors and social support x stressors were entered on the second step.

In each of the following tables, the adjusted R^2 value, *F*-values for each step, and the *F*-value for the R^2-change, beta weights, and their *t*-values are presented. The main effect results are taken from step 1.

Hopelessness

Table 9 displays the results of the multiple regression analysis with hopelessness as the outcome variable.

Table 9. *Results for Hopelessness Regressed on Stressors, Disposition, Social Support and Health Status (N = 45)*

Variable	Beta	*t*
Main Effects		
Hassles	-.225	-1.302
Life events	.072	.480
Meaning in life	-.055	-.331
Locus of control	.232	1.292
Health locus of control	-.220	-1.320
Optimism	-.596	-2.954**
Social support network	-.081	-.491
Social support satisfaction	.036	.207
Self-rated health change	-.185	-1.326
Disability (ADL)	.102	.603
Symptom frequency	.063	.271
Symptom intensity	-.109	-.397
(Adj. R^2 = .27, F = 2.39*)		
Interaction Effects		
Hassles x Meaning in life	-.077	-.297
Life events x Meaning in life	-.082	-.261
Hassles x Locus of control	.335	.978
Life events x Locus of control	-.134	-.520
Hassles x Health locus of control	.281	.925
Life events x Health locus of control	-.374	-1.706
Hassles x Optimism	.380	1.064
Life events x Optimism	-.067	-.272
Hassles x Social support network	.053	.176
Life events x Social support network	.013	.049
Hassles x Social support satisfaction	.511	1.540
Life events x Social support satisfaction	-.234	-.778
(Adj. R^2 = .28, F = 1.72)		
(R^2 chg F = 1.03)		

* $p < .05$, ** $p < .01$

For the main effects, the adjusted R^2 is significant and accounts for a moderate amount of the variance in hopelessness. Optimism predicts hopelessness and, as expected, is negatively related. After adding the interaction effects, neither the adjusted R^2 nor the R^2-change are significant.

In the bivariate analysis (p. 90), stronger meaning in life, stronger optimism, and a larger social support network were related to decreased hopelessness, and weaker personal control was associated with increased hopelessness. In contrast, the multivariate analysis, with statistical control applied, demonstrated an association between stronger optimism and decreased hopelessness only.

Anxiety

The results of the multiple regression analysis, with anxiety as the dependent variable, are presented in Table 10.

Table 10. *Results for Anxiety Regressed on Stressors, Disposition, Social Support and Health Status (N = 45)*

Variable	Beta	*t*
Main Effects		
Hassles	.677	4.093**
Life events	.167	1.169
Meaning in life	-.034	-.216
Locus of control	-.083	-.485
Health locus of control	.057	.356
Optimism	-.183	-.945
Social support network	-.116	-.741
Social support satisfaction	.112	.678
Self-rated health change	-.148	-1.114
Disability (ADL)	.035	.216
Symptom frequency	.083	.373
Symptom intensity	-.131	-.498
(Adj. R^2 = .33, F = 2.85**)		
Interaction Effects		
Hassles x Meaning in life	-.182	-.740
Life events x Meaning in life	-.063	-.209
Hassles x Locus of control	-.036	-.111
Life events x Locus of control	-.328	-1.344
Hassles x Health locus of control	.198	.686
Life events x Health locus of control	-.097	-.469
Hassles x Optimism	-.122	-.359
Life events x Optimism	-.218	-.933
Hassles x Social support network	.106	.371
Life events x Social support network	.006	.023
Hassles x Social support satisfaction	.578	1.835
Life events x Social support satisfaction	-.329	-1.152
(Adj. R^2 = .35, F = 2.01)		
(R^2 chg F = 1.08)		

** $p < .01$

On step 1, the adjusted R^2 is significant, accounting for a moderate proportion of the variance in anxiety. Hassles predict anxiety and relate positively, as expected. On step 2, after adding the interaction effects, neither the adjusted R^2 nor the R^2-change are significant.

In the bivariate analysis (p. 90) higher levels of hassles and life events were both related to increased anxiety. However, in the multivariate analysis, with statistical control applied, only the relation between higher levels of hassles and increased anxiety was maintained.

Depression

The results for the multiple regression analysis, with depression as the dependent variable, are displayed in Table 11.

Table 11. *Results for Depression Regressed on Stressors, Disposition, Social Support and Health Status (N = 45)*

Variable	Beta	*t*
Main Effects		
Hassles	.493	2.932**
Life events	-.034	-.232
Meaning in life	-.047	-.296
Locus of control	-.295	-1.685
Health locus of control	.173	1.067
Optimism	-.476	-2.426*
Social support network	-.098	-.612
Social support satisfaction	-.035	-.210
Self-rated health change	-.148	-1.092
Disability (ADL)	-.031	-.186
Symptom frequency	-.287	-1.277
Symptom intensity	.108	.404
(Adj. R^2 = .31, F = 2.68*)		
Interaction Effects		
Hassles x Meaning in life	.062	.238
Life events x Meaning in life	-.160	-.501
Hassles x Locus of control	-.446	-1.286
Life events x Locus of control	.069	.263
Hassles x Health locus of control	-.318	-1.033
Life events x Health locus of control	-.163	-.733
Hassles x Optimism	-.681	-1.882
Life events x Optimism	-.078	-.314
Hassles x Social support network	.136	.446
Life events x Social support network	.319	1.186
Hassles x Social support satisfaction	.035	.103
Life events x Social support satisfaction	-.233	-.765
(Adj. R^2 = .26, F = 1.66)		
(R^2 chg F = .82)		

* $p < .05$, ** $p < .01$

Examining the main effects, the adjusted R^2 is significant, and accounts for a moderate proportion of the variance in depression. Both optimism and hassles predict depression. Beta weights indicate that hassles is a marginally stronger predictor. As expected, hassles has a positive relation with depression and optimism has a negative association.

Turning to the interaction effects, the adjusted R^2 is not significant. Instead, there is a decrease in explained variance due to the increase in degrees of freedom. The R^2-change is also not significant.

The pattern of findings from the regression is similar to that found in the bivariate analysis (p. 90). However, with statistical control applied, the association between a weaker sense of control over health and increased depression was not maintained.

Negative affect

The summary results on the multiple regression analysis, with negative affect as the dependent variable, are displayed in Table 12.

Table 12. *Results for Negative Affect Regressed on Stressors, Disposition, Social Support and Health Status (N = 45)*

Variable	Beta	*t*
Main Effects		
Hassles	.734	4.708**
Life events	.132	.985
Meaning in life	-.202	-1.361
Locus of control	-.338	-2.088*
Health locus of control	-.103	-.686
Optimism	-.152	-.834
Social support network	.062	.422
Social support satisfaction	.077	.494
Self-rated health change	-.092	-.734
Disability (ADL)	-.071	-.466
Symptom frequency	-.063	-.300
Symptom intensity	.128	.516
(Adj. R^2 = .41, F = 3.55**)		
Interaction Effects		
Hassles x Meaning in life	.020	.100
Life events x Meaning in life	-.224	-.925
Hassles x Locus of control	-.567	-2.153*
Life events x Locus of control	-.231	-1.167
Hassles x Health locus of control	-.450	-1.924
Life events x Health locus of control	-.194	-1.154
Hassles x Optimism	-.520	-1.891
Life events x Optimism	-.062	-.329
Hassles x Social support network	.085	.368
Life events x Social support network	.178	.874
Hassles x Social support satisfaction	-.034	-.133
Life events x Social support satisfaction	-.141	-.608
(Adj. R^2 = .58, F = 3.49**)		
(R^2 chg F = 2.04)		

* $p < .05$, ** $p < .01$

Examining the main effects, the adjusted R^2 is significant, and accounts for a moderate proportion of the variance in negative affect. Both hassles and locus of control predict negative affect, with hassles the stronger predictor. As expected, hassles has a positive association with negative affect. Locus of control (external) has a negative relation with

negative affect, which does not agree with the conceptual expectation. Both of the significant main effects were also involved in a significant interaction effect, which suggests a different interpretation than if they were main effects exclusively. The main effects should be regarded as average effects of the moderator variable.

After adding the interaction effects, the adjusted R^2 is significant, accounting for a large proportion of the variance in negative affect. The R^2-change is not significant, although it is marginally nonsignificant ($F = 2.04, p = .08$). Locus of control x hassles predicts negative affect.

To interpret the locus of control x hassles interaction, a subgroup analysis using a median split (on locus of control) was performed. Regressions were run on low and high groups, with all other main effects present in the equation as control variables. The constants and unstandardised slopes were examined. The interaction revealed that hassles impact on negative affect more strongly for subjects whose locus of control orientation is internal ($B = .506$), than for subjects whose orientation is external ($B = .451$). This finding does not support the theoretical expectation that an internal locus of control orientation will buffer the effect of stressors on well-being outcomes. A possible explanation for this finding is provided in the Discussion and Conclusion chapter.

In the bivariate analysis (p. 90), locus of control did not relate to negative affect. However, in the regression locus of control emerged as a moderator of the relation between hassles and negative affect. Higher levels of hassles was associated with negative affect in people with a more internal locus of control orientation.

Positive affect

The summary results of the multiple regression, with positive affect as the dependent variable, are presented in Table 13.

Table 13. *Results for Positive Affect Regressed on Stressors, Disposition, Social Support and Health Status (N = 45)*

Variable	Beta	*t*
Main Effects		
Hassles	.086	.534
Life events	.139	.996
Meaning in life	.143	.924
Locus of control	-.470	-2.793**
Health locus of control	-.449	-2.883**
Optimism	-.240	-1.273
Social support network	.290	1.893
Social support satisfaction	.049	.303
Self-rated health change	.012	.091
Disability (ADL)	-.078	-.491
Symptom frequency	-.110	-.510
Symptom intensity	.343	1.334
(Adj. R^2 = .37, F = 3.11**)		
Interaction Effects		
Hassles x Meaning in life	-.185	-.721
Life events x Meaning in life	.054	.173
Hassles x Locus of control	.551	1.634
Life events x Locus of control	-.131	-.517
Hassles x Health locus of control	-.084	-.281
Life events x Health locus of control	-.136	-.632
Hassles x Optimism	.213	.605
Life events x Optimism	-.053	-.217
Hassles x Social support network	-.048	-.160
Life events x Social support network	.118	.452
Hassles x Social support satisfaction	.258	.789
Life events x Social support satisfaction	-.313	-1.055
(Adj. R^2 = .30, F = 1.80)		
(R^2 chg F = .76)		

* $p < .05$, ** $p < .01$

On step 1, the adjusted R^2 is significant, and accounts for a moderate proportion of the variance in positive affect. Both locus of control and health locus of control predict positive affect. An examination of the beta weights revealed that locus of control is the marginally stronger predictor. As expected, both locus of control (external) and health

locus of control (external) related negatively to positive affect. After adding the interaction effects, the R^2-change is not significant.

In the bivariate analysis (p. 90), stronger meaning in life, a larger social support network, and increased social support satisfaction were related to increased positive affect, and weaker personal control and weaker control over health were associated with decreased positive affect. Whereas, in the regression, with statistical control applied, the only associations maintained with decreased positive affect were between weaker personal control and weaker control over health.

Life satisfaction

Finally, the summary results for the multiple regression, with life satisfaction as the dependent variable, are displayed in Table 14.

Table 14. *Results for Life Satisfaction Regressed on Stressors, Disposition, Social Support and Health Status (N = 45)*

Variable	Beta	*t*
Main Effects		
Hassles	-.161	-1.059
Life events	.004	.031
Meaning in life	.321	2.215*
Locus of control	-.054	-.345
Health locus of control	.120	.820
Optimism	.592	3.338**
Social support network	-.118	-.082
Social support satisfaction	-.011	-.078
Self-rated health change	.185	1.517
Disability (ADL)	-.033	-.222
Symptom frequency	-.149	-.734
Symptom intensity	.187	.777
(Adj. R^2 = .44, F = 3.89**)		
Interaction Effects		
Hassles x Meaning in life	-.315	-1.725
Life events x Meaning in life	.113	.508
Hassles x Locus of control	-.102	-.425
Life events x Locus of control	.207	1.141
Hassles x Health locus of control	.264	1.234
Life events x Health locus of control	.006	.041
Hassles x Optimism	.072	.287
Life events x Optimism	-.198	-1.137
Hassles x Social support network	-.400	-1.883
Life events x Social support network	.252	1.347
Hassles x Social support satisfaction	.125	.534
Life events x Social support satisfaction	-.070	-.329
(Adj. R^2 = .64, F = 4.32**)		
(R^2 chg F = 2.52*)		

* $p < .05$, ** $p < .01$

On the first step, the adjusted R^2 is significant, and accounts for a moderate proportion of the variance in life satisfaction. Both optimism and meaning in life predict life satisfaction. The beta weights indicate that optimism is the stronger predictor. As expected, both optimism and meaning in life relate positively to life satisfaction. On

the second step, the adjusted R^2 is significant, accounting for a large proportion of the variance in life satisfaction. The R^2-change is also significant. However, none of the interaction effects are singularly significant. Thus the interaction effect is shared among the variables, rather than located in any specific variable or variables.

In the bivariate analysis (p. 90) stronger meaning in life, stronger optimism, and a larger social support network were related to improved life satisfaction, and weaker personal control was associated with decreased life satisfaction. Whereas, in the multivariate analysis, with statistical control applied, the only relations supported were between increased life satisfaction with stronger life meaning and stronger optimism.

Summary

To summarise, in this series of regressions on the determinants of psychological well-being there were several significant main effects and a few significant interactions. However, relative to the number of significant findings predicted by the model, these were not extensive.

Several variables had direct relations to positive well-being outcomes. People with a more external locus of control and external health locus of control orientation tended to experience decreased positive affect. Persons with higher levels of meaning in life and optimism tended to report better life satisfaction.

A number of main effects were associated with negative well-being outcomes. People with stronger dispositional optimism were prone to lower levels of hopelessness and lessened depression. People with weaker personal control were inclined to experience decreased levels of negative affect. Persons who reported higher levels of hassles were prone to increased anxiety, higher levels of depression, and higher levels of negative affect.

Disposition and social support did not moderate the effects of stressors on either positive or negative well-being outcomes, with a single exception. A higher level of hassles was

related to increased negative affect for people with a more internal locus of control.

Overall results of these analyses provide some support for the theoretical model. Findings suggest relations among the psychosocial factors, when viewed at a single point in time, tend to be main rather than moderating effects.

Determinants of physical health status

Although in the model, disposition and social support are both proposed to moderate the relation between psychological well-being and physical health status, two separate series of regressions were performed. To increase the statistical power in a small sample, particularly when testing for interaction effects, it is preferable to limit the number of independent variables entered into the equation. It was already established in the bivariate analysis that neither of the social support variables correlated with any of the health status outcomes. Therefore, the need for statistical control was reduced, and greater emphasis was placed on maximising statistical power.

Hierarchical multiple regression was used to examine the hypothesis that psychological well-being relates to physical health status, and that this relation is moderated by disposition and social support. In the first analysis, the four physical health status variables, in turn, were treated as dependent variables. The well-being variables and the dispositional variables were entered on step 1. The product terms, well-being x disposition, were entered on step 2.

In the series of regressions predicting physical health status outcomes, none of the adjusted R^2 values are significant for the main effects. With the interaction effects added, the adjusted R^2 values and R^2-changes are also not significant. To simplify the text, the summary tables (F-1 to F-4) for these regressions are provided in Appendix F.

Overall the results of the regressions do not provide evidence that psychological well-being relates to physical health status, or that disposition moderates the relation between

well-being and health status.

In the second set of analyses examining social support as a moderator, the four health status variables, in turn, were again considered as dependent variables. The well-being variables and the social support variables were entered on step 1. The product terms, well-being x social support, were entered on step 2.

The results for both main effects and interaction effects were not significant and therefore, to maintain clarity in the text, the result tables can be found in Appendix F (Tables F-5 to F-8). The findings do not indicate that well-being and health status are associated, or that social support moderates the relation between well-being and health status.

Determinants of social support

To examine the hypothesis that physical health status is associated with social support, standard multiple regression analysis was employed. Social support network and social support satisfaction were the dependent variables, in turn. Self-rated health change, disability (ADL), symptom frequency and symptom intensity were the independent variables, entered together. When predicting either social support network or social support satisfaction the adjusted R^2 is not significant.

Next, standard multiple regression analysis was utilised to examine the hypothesis that disposition is related to social support. Social support network and social support satisfaction were the dependent variables in turn. Meaning in life, locus of control, health locus of control and optimism were the independent variables, entered together.

When predicting social support network, the adjusted R^2 is significant, $F(4,40) = 2.96$, $p < .05$, accounting for a small proportion of the variance in social support network. However, none of the dispositional variables singularly predict social support network. This differed from the bivariate analysis (p. 92), which found stronger life meaning and stronger optimism to be related to a larger support network, and a weaker sense of

personal control to be associated with a smaller network. The adjusted R^2 when predicting social support satisfaction is also significant, $F(4,40) = 3.77$, $p < .05$, and accounts for a small proportion of the variance in social support satisfaction. Meaning in life predicts social support satisfaction ($t = 3.65$, $p < .01$), and, as expected, has a positive association. The bivariate analysis (p. 92) also found stronger life meaning to be associated with a larger social support network.

The results from these regressions indicate that physical health status and social support are not related, however, they suggest that people with stronger life meaning will tend to experience increased social support satisfaction.

Determinants of stressors

Standard multiple regression analysis was also utilised to examine the hypothesis that physical health status is related to stressors. Hassles and life events were the dependent variables, in turn. Self-rated health change, disability (ADL), symptom frequency and symptom intensity were the independent variables, entered together.

The adjusted R^2 is significant, $F(4,40) = 3.93$, $p < .01$, accounting for a small proportion of the variance in hassles. Both symptom intensity ($t = 3.309$, $p < .01$) and disability (ADL) ($t = 2.570$, $p < .05$) predict hassles. The beta weights indicate that symptom intensity is the stronger predictor. Symptom intensity has a positive relation to hassles, as expected. However, disability (ADL) also has a positive relation to hassles, which is conceptually puzzling. A possible reason for this finding is discussed in chapter 9. In the bivariate analysis (p. 92), stronger symptom intensity was also related to a higher level of hassles, but disability was unrelated to hassles. With life events as the dependent variable, the adjusted R^2 is not significant ($F(4,40) = .73$, ns). In the bivariate analysis, (p. 92) physical health status and life events were also unrelated.

The results provide some support for an association between health status and stressors, suggesting that physical health status has an affect on hassles but not on major life events.

Conclusion

Clearly, the most consistent relations in the model were found between the dispositional variables and psychological well-being. Stronger life meaning, stronger optimism, a stronger sense of personal control and a stronger sense of control over health were all related to better psychological well-being. An individual's level of hassles was also related to his or her psychological well-being. In particular, higher levels of hassles were associated with increased negative affect, anxiety and depression. In contrast, a person's social support network size or degree of satisfaction with his or her network was generally not associated with psychological outcomes.

Physical health status, in particular higher levels of symptom frequency and symptom intensity, were related to higher levels of hassles, but were not associated with major life events.

Contrary to expectations, psychological well-being and physical health status were not associated. Further, the role of disposition and social support as moderators of the impact of stressors on well-being, or the impact of emotional states on physical health, was not supported. Physical health status was also unrelated to social support. In contrast, stronger life meaning was associated with increased social support satisfaction.

CHAPTER 6

LONGITUDINAL RESULTS: TESTING FOR CHANGE OVER TIME

This chapter focuses on data collected during the longitudinal phase of the study. The findings are based on the scores of 12 participants (a sub-group of the cross-sectional sample) who completed measures seven times, at approximately monthly intervals. Unlike the previous chapter, which examined relationships among factors in the theoretical model at a single point in time, the present chapter focuses on changes in factors as they relate to changes in other factors, over time. Hypotheses arising out of relations in the theoretical model are tested. Throughout this chapter comparative comments highlight differences and similarities between the cross-sectional and longitudinal findings. The within-subject regression findings are described in the present chapter and will be more thoroughly interpreted in chapter 9.

The constructs and variables included in the longitudinal analyses, as well as information about how the variables were represented in scores are presented in Table 15. Details about data treatment were provided earlier in the Method chapter. As explained, 12 subjects x 7 data collection points created 84 episodes, providing, in effect, an *N* of 84.

The format of this chapter is similar to the previous chapter. It begins with an examination of variable distributions. Following that, bivariate statistics and a discussion of the key bivariate relationships are presented. The second half of the chapter presents a series of within-subject multiple regression analyses.

Table 15. *Variables Present in the Longitudinal Analyses, Type of Score and Number of Assessments*

Variable	Type of score (number)
STRESSORS	
Hassles	deviation score (7)
Life events	deviation score (7)
DISPOSITION	
Meaning in life	averaged score (2)
Locus of control	averaged score (2)
Health locus of control	averaged score (2)
Optimism	averaged score (2)
SOCIAL SUPPORT	
Social support network	averaged score (2)
Social support satisfaction	averaged score (2)
PSYCHOLOGICAL WELL-BEING	
Hopelessness	deviation score (7)
Anxiety	deviation score (7)
Depression	deviation score (7)
Negative affect	deviation score (7)
Positive affect	deviation score (7)
Life satisfaction	deviation score (7)
PHYSICAL HEALTH STATUS	
Symptom frequency	deviation score (7)
Symptom intensity	deviation score (7)
Disability (ADL)	deviation score (7)
Self-rated health change	deviation score (7)
Other-rated health change	deviation score (5)
Disability (FIM)	deviation score (6)
Impairment status	deviation score (6)
Neurologic dysfunction	deviation score (6)

Four health status variables are reported in this chapter that did not appear in the previous chapter. Measures for these variables were obtained by a physician during the physical examinations (refer to Method chapter). Three of the measures were collected six times (T2 to T7): disability (FIM), impairment status, and neurologic dysfunction. The other measure, other-rated health change, was available on five occasions (T3 to T7), because a reference point for health was established at the first physical examination.

UNIVARIATE CHARACTERISTICS

The variable distributions were inspected and the majority of variables did not depart substantially from normality. Hopelessness, disability (FIM), and impairment status each demonstrated restricted variability. This is an indication that subjects were relatively stable in regard to their level of hopelessness, ability to perform everyday tasks (as measured by the FIM), and overall impairment.

BIVARIATE ANALYSES

Pearson correlations were computed to examine the interrelation of the variables within and between each major construct. The within-subject correlations, reported for the stressor, psychological well-being and physical health status variables, reflect changes in one variable in relation to changes in another variable. In most prior research between-subject correlations are cited, and these associations are not directly comparable to the present findings. Intercorrelations are not provided for the dispositional and social support variables which were not created from longitudinal data.

P values, based on a two-tailed test of significance, are given either in parentheses or in the appropriate table. In addition, a complete correlation matrix presenting the intercorrelations of all the variables can be found in Appendix E (Table E-2).

Interrelationships within constructs

Changes in hassles and life events correlate at a low level (r = .17, ns), providing support for the theory that hassles and life events capture two different aspects of stressors, even when assessed over time. This association is similar in magnitude to that found in the between-subject correlation.

The intercorrelations of changes in the psychological well-being variables (hopelessness, anxiety, depression, negative affect, positive affect and life satisfaction) were considered next. The associations of the well-being variables are given in Table 16.

Table 16. *Intercorrelations of Psychological Well-being Variables (N = 84)*

Variables	ANX	DEP	NA	PA	LS
HP	.25*	.29**	.26*	-.18	-.31**
ANX	-	.68**	.70**	-.33**	-.31**
DEP		-	.57**	-.39**	-.37**
NA			-	-.34**	-.38**
PA				-	.38**

** $p < .01$, * $p < .05$

Note. ANX-Anxiety, DEP-Depression, NA-Negative affect, PA-Positive affect, LS-Life satisfaction, HP-Hopelessness

Changes in the negative well-being variables (hopelessness, anxiety, depression and negative affect) are moderately to strongly associated, with the exception of hopelessness which demonstrates a weak relation with the other negative well-being variables. This may be a consequence of the restricted variability in hopelessness. Interestingly, the same pattern of association between hopelessness and other negative well-being variables was found in the cross-sectional group. Changes in the two positive well-being variables (positive affect and life satisfaction) are correlated at a moderate level. The positive and negative well-being variables are moderately and inversely related, with the exception of hopelessness and positive affect, which show a weak inverse relation.

Generally the pattern of the within-subject correlations is similar to the between-subject correlations. One noticeable exception is the relation between hopelessness and life satisfaction. The association between these variables is considerably stronger in the cross-sectional group, perhaps because hopelessness and life satisfaction are strongly related at any given time, but changes in hopelessness do not relate to changes in life satisfaction, when considered over time.

Table 17 displays the intercorrelations of the physical health status variables (self-rated health change, disability (ADL), symptom frequency, symptom intensity, other-rated health change, impairment status, disability (FIM), and neurologic dysfunction). The sample size drops to 60 whenever other-rated health is included in an analysis. Overall, the variables are weakly related, with two notable exceptions. Changes in self-rated health are strongly associated with changes in other-rated health, and changes in symptom intensity are strongly related to changes in symptom frequency. Overall, the pattern of between-subject and within-subject correlations are somewhat different. Relations between self-rated health change and the other health variables are stronger in the longitudinal group. It is reasonable to expect that changes in self-rated health will relate to changes in the other health indicators. The association between symptom frequency and symptom intensity is stronger in the cross-sectional group. Furthermore, disability (ADL) shows a considerably weaker relation to symptom intensity in the within-subject group.

Table 17. *Intercorrelations of Physical Health Status Variables (N = 60)*

Variables	ADL	SYMFR	SYMIN	OHC	IMP	FIM	NDYS
SHC	.17	-.31*	-.15	.67**	.12	-.06	-.05
ADL	-	-.37**	-.24	.09	-.15	-.08	.08
SYMFR		-	.65**	-.19	-.23	.10	-.11
SYMIN			-	-.16	-.12	-.02	.16
OHC				-	-.04	.03	-.17
IMP					-	-.14	.25
FIM						-	-.24

** $p < .01$, * $p < .05$

Note. ADL-Disability, SYMFR-Symptom frequency, SYMIN-Symptom intensity, OHC-Other-rated health change, IMP-Impairment status, FIM-Disability, NDYS-Neurologic dysfunction, SHC-Self-rated health change

Associations between psychological well-being and other constructs in the model

The correlations between psychological well-being, the main psychological focus of the model, and every other major construct in the model (stressors, disposition, social support, physical health status) are presented in Table 18.

Table 18. *Correlations of Well-being Variables with Stressor, Dispositional, Social Support and Health Status Variables (N = 60)*

Variables	HP	ANX	DEP	NA	PA	LS
HASS	.05	.19	.19	.31*	-.12	-.25*
LE	.31*	.25*	.09	.22	-.18	-.23
MIL	.01	-.05	-.07	-.09	-.01	.00
LOC	.06	-.02	-.02	.13	.02	-.03
HLOC	-.07	.05	-.01	-.01	.09	.07
OPT	.05	-.02	.07	-.13	.09	-.06
SSN	.04	.02	.00	-.19	.03	-.00
SSS	.14	.05	.01	-.00	-.06	-.04
SHC	-.22	-.26*	-.06	-.22	.17	.08
ADL	-.08	-.28*	-.12	-.20	.28*	.02
SYMFR	-.17	.15	.06	.14	-.24	-.03
SYMIN	.02	.11	.09	.06	-.23	-.21
OHC	-.06	-.35**	-.21	-.24	.22	.29*
IMP	-.13	.21	.09	.17	.06	-.07
FIM	-.01	.11	.08	.01	.09	.07
NDYS	-.04	.05	.19	-.01	.00	-.06

** $p < .01$, * $p < .05$

Note. HP-Hopelessness, ANX-Anxiety, DEP-Depression, PA-Positive affect, NA-Negative affect, LS-Life satisfaction, HASS- Hassles, LE-Life events, MIL-Meaning in life, LOC-Locus of control, HLOC-Health locus of control, OPT-Optimism, SSN-Social support network, SSS-Social support satisfaction, SHC-Self-rated health change, ADL-Disability, SYMFR-Symptom frequency, SYMIN-Symptom intensity, OHC-Other-rated health change, IMP-Impairment status, FIM-Disability, NDYS-Neurologic dysfunction

The most striking feature about the pattern of correlations is that, generally, stressors, disposition, social support and health status are only weakly associated with changes in psychological well-being. Hassles show the strongest associations with negative affect and life satisfaction, and, in contrast, life events relate most strongly to hopelessness and anxiety. Although the magnitude of these correlations are not particularly strong, they

may suggest that minor stressors and major stressors relate to different aspects of well-being. Overall, out of the well-being variables, anxiety has the strongest relation with the other variables.

Generally, the within-subject correlations are considerably weaker than the between-subject correlations. In the cross-sectional group the strongest relationships with well-being occurred with hassles, meaning in life and optimism. For example, hassles correlated with anxiety, $r = .64$, meaning in life with life satisfaction, $r = .56$, and optimism with life satisfaction, $r = .65$. In the longitudinal group, without exception, these and other associations show a substantial weakening, and in many cases variables are virtually unrelated. The stability of disposition might explain the weakening of the disposition - well-being association.

Associations among health status, social support, stressor and dispositional variables

Next, some relationships proposed in the model that do not directly involve psychological well-being were examined. These focused on the relation of physical health status to social support and stressors, and the association between disposition and social support. The correlations of the social support and stressor variables with the health status and dispositional variables are displayed in Table 19.

Table 19. *Correlations of Social Support and Stressor Variables with Health Status and Dispositional Variables (N = 60)*

Variables	SSN	SSS	HASS	LE
SHC	.06	-.01	.10	-.25*
ADL	-.23	-.06	-.10	-.13
SYMFR	.14	.12	.15	.06
SYMIN	.22	.20	.36**	.12
OHC	.00	.00	-.16	-.31*
IMP	-.08	-.04	-.07	.20
FIM	-.11	-.01	-.01	-.04
NDYS	-.02	-.07	.17	-.06
MIL	.18	.11	-.05	.10
LOC	-.67**	-.12	-.15	.02
HLOC	-.01	-.25	.06	-.04
OPT	.66**	.10	.13	.14

** $p < .01$, * $p < .05$

Note. SSN-Social support network, SSS-Social support satisfaction, Hass-Hassles, LE-Life events, SHC-Self-rated health change, ADL-Disability, SYMFR-Symptom frequency, SYMIN-Symptom intensity, OHC-Other-rated health change, IMP-Impairment status, FIM-Disability, NDYS- Neurologic Dysfunction, MIL-Meaning in life, LOC-Locus of control, HLOC-Health locus of control, OPT-Optimism

The health status variables have consistent weak associations with the social support variables. They are also weakly correlated with changes in stressors, with two exceptions. Other-rated health change is moderately related to life events, and symptom intensity is moderately associated with hassles. Changes in stressors are weakly associated with the dispositional variables.

Patterns of correlations from the cross-sectional and longitudinal analyses are similar for social support and stressor variables in relation to health status variables. They are also similar, though marginally weaker, for dispositional variables with stressor variables.

WITHIN-SUBJECT MULTIPLE REGRESSION ANALYSES

Within-subject multiple regression analysis, using SPSS-PC REGRESSION, was used. As mentioned earlier, the data was derived from 12 cases using (seven) repeated measures over monthly intervals. The *N* for the regressions varies from 84 to 60 depending on which variables are present in the equation. When all health status variables are included the *N* drops to 60.

The hypotheses test some of the relations among the psychosocial and physical health factors in the theoretical model as they change over the seven month period of this study. Unlike the previous chapter, social support does not feature as an outcome variable. It was not conceptually sensible to treat social support, which is a between-subject variable, as a dependent variable in the within-subject regressions.

There were two other differences in the within-subject regressions. Firstly, the four additional health status variables were included when appropriate, as either dependent or independent variables. Secondly, time was included as a variable in order to examine and control for any linear time trend in the outcome variables. Time was defined as a variable with seven values (T1 to T7), each value corresponding to one of the seven data collection points. As explained in the Method chapter, deviation scores were used in all regressions.

Examination of the outliers from the many regressions in this chapter revealed a few outliers, although none were greater than 5. Re-analysing the regressions with the outliers removed did not change the pattern of findings and the outliers were therefore tolerated. Inspection of the plots of the residuals revealed that there were no marked departures from linearity or homoscedasticity.

Determinants of psychological well-being

It was hypothesised that stressors, disposition, social support, and health status, would

each directly impact on psychological well-being over time, and that disposition and social support would both moderate the impact of stressors on well-being. In six hierarchical regressions, the well-being variables, in turn, were treated as dependent variables. To test for main effects, time, stressor, disposition, social support, and health status variables, were entered on the first step. To test for moderating effects, the product terms of disposition x stressors and social support x stressors were entered on the second step.

In this series of regressions there were many non-significant results. To simplify the text, only summary tables that contain statistically significant ($p < .05$) results are presented in the chapter. The other result tables are provided in Appendix G (Tables G-1 to G-4). In all result tables, the adjusted R^2 value, F-values for each step, and the F-value for the $R2$-change, beta weights, and their t-values are presented. The main effects results are taken from step 1.

Hopelessness

Table 20 displays the summary results of the multiple regression analysis with hopelessness as the outcome variable.

Table 20. *Results for Hopelessness Regressed on Stressors, Disposition, Social Support, Health Status and Time (N = 60)*

Variable	Beta	*t*
Main Effects		
Hassles	.081	.543
Life events	.327	2.254*
Meaning in life	-.047	-.320
Locus of control	-.022	-.097
Health locus of control	.020	.109
Optimism	.056	.239
Social support network	-.189	-.562
Social support satisfaction	.216	1.019
Self-rated health change	-.355	-1.720
Disability (ADL)	-.195	-1.271
Symptom frequency	-.539	-2.757**
Symptom intensity	.201	1.064
Other-rated health change	.213	1.039
Impairment status	-.287	-1.819
Disability (FIM)	-.053	-.380
Neurologic dysfunction	-.038	-.221
Time	.037	.216
(Adj. R^2 = .08, F = 1.31)		
Interaction Effects		
Hassles x Meaning in life	.197	1.478
Life events x Meaning in life	-.130	-.877
Hassles x Locus of control	-.956	-2.214*
Life events x Locus of control	1.156	3.405**
Hassles x Health locus of control	-.442	-1.792
Life events x Health locus of control	.633	2.538*
Hassles x Optimism	.282	.808
Life events x Optimism	-.011	-.048
Hassles x Social support network	-1.064	-1.649
Life events x Social support network	.473	1.265
Hassles x Social support satisfaction	-.058	-.193
Life events x Social support satisfaction	.180	.719
(Adj. R^2 = .38, F = 2.26*)		
(R^2 chg F = 2.71*)		

* $p < .05$, ** $p < .01$

Examining the main effects, the adjusted R^2 is not significant. After adding the

interaction effects, the adjusted R^2 is significant, accounting for a moderate proportion of the variance in hopelessness. The R^2-change is also significant. Hassles x locus of control, life events x locus of control, and life events x health locus of control each predict hopelessness. Of the three, beta weights suggest that life events x locus of control is the strongest predictor.

To interpret the three interactions, and all subsequent significant interactions, subgroup analyses using median splits were performed. Regressions were run on low and high (locus of control and health locus of control) groups, with all other main effects present in the equation as control variables. For each interaction effect, an examination was made of the constants and unstandardised slopes.

In the case of hassles x locus of control, hassles impact on hopelessness more strongly when locus of control is external (B = .034) than when locus of control is internal (B = .003). For people with an external orientation, as hassles increase, hopelessness also increases. In internally orientated people, as hassles increase, hopelessness does not change.

An examination of the life events x locus of control interaction revealed a similar pattern. Life events impact on hopelessness more strongly when locus of control is external (B = .240) than when locus of control is internal (B = .047). As life events increase, hopelessness also increases, and this relation is stronger for external people.

An inspection of the life events x health locus of control interaction shows a different pattern. Life events impact on hopelessness more strongly when health locus of control is internal (B = .199) than when health locus of control is external (B = .122). As life events increase, hopelessness also increases. This relation is slightly stronger for people with an internal health locus of control. This finding does not agree with the conceptual expectation that persons with an internal health locus of control will cope with stressors more effectively than persons with an external health locus of control.

The pattern of significant relations in the within-subject regression is different from the

between-subject regression. Stronger optimism was related to less hopelessness in the between-subject sample. Whereas, in the within-subject group, higher levels of hassles and life events are both related to more hopelessness for people with a weaker sense of personal control. Further, higher levels of life events are related to more hopelessness for people with a stronger sense of control over their health.

Life satisfaction

The summary results for the multiple regression, with life satisfaction as the dependent variable, are displayed in Table 21.

Table 21. *Results for Life Satisfaction Regressed on Stressors, Disposition, Social Support, Health Status and Time (N = 60)*

Variable	Beta	*t*
Main Effects		
Hassles	-.121	-.739
Life events	-.120	-.752
Meaning in life	.023	.145
Locus of control	.071	.289
Health locus of control	.046	.224
Optimism	-.080	-.310
Social support network	.202	.548
Social support satisfaction	-.090	-.389
Self-rated health change	-.092	-.404
Disability (ADL)	-.021	-.123
Symptom frequency	.154	.720
Symptom intensity	-.232	-1.122
Other-rated health change	.254	1.128
Impairment status	-.054	-.314
Disability (FIM)	.012	.078
Neurologic dysfunction	-.002	-.010
Time	.154	.828
(Adj. R^2 = -.11, F = .67)		
Interaction Effects		
Hassles x Meaning in life	-.526	-3.854**
Life events x Meaning in life	.298	1.964
Hassles x Locus of control	-.595	-1.348
Life events x Locus of control	.309	.890
Hassles x Health locus of control	-.074	-.292
Life events x Health locus of control	.199	.781
Hassles x Optimism	-.067	-.188
Life events x Optimism	-.507	-2.076*
Hassles x Social support network	-.438	-.664
Life events x Social support network	.817	2.138*
Hassles x Social support satisfaction	.442	1.447
Life events x Social support satisfaction	-.501	-1.958
(Adj. R^2 = .35, F = 2.12*)		
(R^2 chg F = 3.49**)		

* $p < .05$, ** $p < .01$

On the first step, the adjusted R^2 is not significant. On the second step, the adjusted R^2

is significant, and accounts for a moderate proportion of the variance in life satisfaction. The R^2-change is also significant. Hassles x meaning in life, life events x optimism and life events x social support network each predict life satisfaction. Beta weights indicate that life events x social support network is the strongest predictor.

The three interactions were interpreted with sub-group analysis using median splits on meaning in life, optimism, and social support network. In the hassles x meaning in life interaction, hassles impact on life satisfaction more strongly when meaning in life is stronger (B = -.091) than when meaning in life is weaker (B = .020). For people with stronger life meaning, as hassles increase, life satisfaction declines. For people with weaker meaning, as hassles increase, life satisfaction improves. This is not sensible from a conceptual perspective, because strong life meaning is expected to provide a protective function against the potential harm of stressors.

Examining the life events x social support network interaction, life events impact on life satisfaction more strongly when social network is larger (B = -.079) than when social support network is smaller (B = .034). For people with larger social support networks, as life events increase, life satisfaction declines. For people with smaller social support networks, as life events increase, life satisfaction improves. This finding is contrary to the conceptual expectation that a large social support network counters the influence of stressors.

An inspection of the life events x optimism interaction revealed that life events impact on life satisfaction more strongly when optimism is stronger (B = -.220) than when optimism is weaker (B = -.018). As life events increase, life satisfaction declines, and this relation is stronger for more highly optimistic people. This finding conflicts with the conceptual assumption that strong optimism will protect against the affect of stressors.

The pattern of results from this series of regressions were different from the between-subject findings. In the between-subject regressions, stronger life meaning and stronger optimism were related to better life satisfaction. In the within-subject group, higher

levels of life events are related to worse life satisfaction for people with larger social support networks and stronger optimism. Similarly, higher levels of hassles are associated with worse life satisfaction for people with stronger life meaning.

Summary

Overall, the regression results provide some support for the theoretical model. Unexpectedly, these finding indicate that changes in health status are not related to changes in psychological well-being over time. This is particularly surprising given the range of well-being factors and health indicators considered. As well as the usual self-report symptom measures, subjects were carefully assessed by a physician using medically derived instruments. The findings suggest that disposition, and to a lesser extent social support, moderate how changes in stressors relate to changes in psychological well-being. However, in many cases the moderating variables function differently from conceptual expectations, and this will be discussed is chapter 9. In an attempt to clarify and further understand these relations at the individual case level, they will be examined in the next chapter.

Generally, the pattern of results from the within-subject regressions were different from those of the between-subject regressions. The most striking difference was that in the between-subject regressions nearly all effects were direct, whereas in the within-subject regressions all effects were interactive. In both the cross-sectional and longitudinal analyses, stressors, disposition and social support demonstrated a relation to psychological well-being. However, evidence does not support an association between physical health status and psychological well-being in either sample.

Determinants of health status

Disposition and social support are both hypothesised to moderate the relation between psychological well-being and physical health status. As in the cross-sectional analysis, two series of regressions were performed, entering moderating effects separately, to increase statistical power. In accord with the cross-sectional findings, the longitudinal

bivariate analysis demonstrated that the social support variables did not correlate with any of the physical health status outcomes, lessening the need for statistical control.

To test the hypothesis that well-being impacts on health status, and that this relation is moderated by disposition and social support, two series of eight within-subject hierarchical regressions were run. In the first series, the physical health status variables, in turn, were treated as dependent variables. The psychological well-being variables, the dispositional variables, and time were entered on step 1. The product terms, well-being x disposition, were entered on step 2.

Summary tables for regressions that contain statistically significant ($p < .05$) results are provided in the text. Summary tables with non-significant results can be found in Appendix H (Tables H-1 to H-5).

Self-rated health change

The summary results of the multiple regression analysis, with self-rated health change as the dependent variable, are presented in Table 22.

Table 22. *Results for Self-rated Health Change Regressed on Well-being, Disposition and Time (N = 60)*

Variable	Beta	*t*
Main Effects		
Hopelessness	-.164	-1.159
Anxiety	-.340	-1.439
Depression	.291	1.427
Positive affect	.144	.841
Negative affect	-.089	-.429
Life satisfaction	-.085	-.511
Meaning in life	.012	.083
Locus of control	.049	.258
Health locus of control	.036	.195
Optimism	.063	.359
Time	-.048	-.330
(Adj. R^2 = -.04, F = .78)		
Interaction Effects		
Hopelessness x Meaning in life	-.136	-.495
Anxiety x Meaning in life	-.073	-.337
Depression x Meaning in life	.024	.096
Positive affect x Meaning in life	.159	.726
Negative affect x Meaning in life	.416	1.825
Life satisfaction x Meaning in life	-.009	-.033
Hopelessness x Locus of control	-.119	-.254
Anxiety x Locus of control	.328	.590
Depression x Locus of control	-.065	-.179
Positive affect x Locus of control	.137	.428
Negative affect x Locus of control	-.062	-.080
Life satisfaction x Locus of control	-.445	-.897
Hopelessness x Health locus of control	.098	.292
Anxiety x Health locus of control	.449	1.100
Depression x Health locus of control	.077	.173
Positive affect x Health locus of control	.541	2.150*
Negative affect x Health locus of control	-.042	-.093
Life satisfaction x Health locus of control	-.219	-.760
Hopelessness x Optimism	.003	.014
Anxiety x Optimism	.638	1.468
Depression x Optimism	-.657	-1.992
Positive affect x Optimism	.439	1.654
Negative affect x Optimism	-.056	-.097
Life satisfaction x Optimism	-.215	-.611
(Adj. R^2 = .46, F = 2.45*)		
(R^2 chg F = 2.88**)		

* $p < .05$, ** $p < .01$

The adjusted R^2 for the main effects is not significant. After adding the interaction terms, the adjusted R^2 becomes significant and accounts for a large proportion of the variance in self-rated health change. The R^2-change is also significant. Positive affect x health locus of control predicts self-rated health change.

The interaction was interpreted with sub-group analysis using a median split on health locus of control. The interaction suggests that positive affect impacts on self-rated health change more strongly if health locus of control is external ($B = .058$) than if health locus of control is internal ($B = .027$). As positive affect increases, self-rated health change improves. This relation is stronger for people with an external health locus of control orientation. This finding does not meet the conceptual expectation that an internal health locus of control orientation leads to better physical health outcomes than an external orientation.

The pattern of results from the within-subject regression differ from those in the between-subject regression. In the between-subject regression none of the variables predicted self-rated health change. Further, in the between-subject regression, the combined variables accounted for almost none of the variance in self-rated health change. This sharply contrasts to the within-subject regression, where nearly half of the variance of self-rated health is explained.

Disability (ADL)

The summary results for the multiple regression, with disability (ADL) as the dependent variable, are presented in Table 23.

Table 23. *Results for Disability (ADL) Regressed on Well-being, Disposition and Time (N = 60)*

Variable	Beta	*t*
Main Effects		
Hopelessness	.007	.057
Anxiety	-.363	-1.750
Depression	.322	1.798
Positive affect	.410	2.736**
Negative affect	-.139	-.766
Life satisfaction	-.254	-1.729
Meaning in life	.106	.810
Locus of control	.023	.144
Health locus of control	-.175	-1.074
Optimism	-.427	-2.781
Time	-.031	-.241
(Adj. R^2 = .20, F = 2.30*)		
Interaction Effects		
Hopelessness x Meaning in life	-.011	-.030
Anxiety x Meaning in life	-.306	-1.065
Depression x Meaning in life	.164	.498
Positive affect x Meaning in life	.173	.589
Negative affect x Meaning in life	.145	.478
Life satisfaction x Meaning in life	-.262	-.742
Hopelessness x Locus of control	-.040	-.064
Anxiety x Locus of control	.601	.809
Depression x Locus of control	-.293	-.603
Positive affect x Locus of control	.252	.593
Negative affect x Locus of control	-1.763	-1.708
Life satisfaction x Locus of control	-1.171	-1.768
Hopelessness x Health locus of control	-.319	-.710
Anxiety x Health locus of control	.197	.362
Depression x Health locus of control	-.589	-1.000
Positive affect x Health locus of control	.144	.428
Negative affect x Health locus of control	-.136	-.224
Life satisfaction x Health locus of control	-.799	-2.076*
Hopelessness x Optimism	-.197	-.609
Anxiety x Optimism	.351	.606
Depression x Optimism	-.444	-1.010
Positive affect x Optimism	.202	.570
Negative affect x Optimism	-1.080	-1.400
Life satisfaction x Optimism	-.781	-1.667
(Adj. R^2 = .04, F = 1.08)		
(R^2 chg F = .68)		

* $p < .05$, ** $p < .01$

The adjusted R^2 for the main effects is significant and accounts for a moderate amount of the variance in ADL. Positive affect predicts ADL, and as expected, relates positively to ADL. This is interesting given that in the bivariate analysis, ADL and positive affect were only weakly related. The interaction effects, when added on the next step, are not significant, and, in fact, the explained variance decreases considerably due to an increase in the degrees of freedom.

The patterns of results from the within-subject regression differ from those of the between-subject regression. In the between-subject regression none of the main effects impacted on ADL.

Impairment status

The summary results of the multiple regression analysis, with impairment status as the dependent variable, are presented in Table 24.

Table 24. *Results for Impairment Status Regressed on Well-being, Disposition and Time (N = 60)*

Variable	Beta	*t*
Main Effects		
Hopelessness	-.230	-1.712
Anxiety	.370	1.651
Depression	-.197	-1.019
Positive affect	.015	.094
Negative affect	.019	.098
Life satisfaction	-.083	-.525
Meaning in life	-.175	-1.237
Locus of control	.197	1.117
Health locus of control	.002	.011
Optimism	.178	1.070
Time	.270	1.971
(Adj. R^2 = .06, F = 1.35)		
Interaction Effects		
Hopelessness x Meaning in life	.266	1.046
Anxiety x Meaning in life	-.527	-2.644*
Depression x Meaning in life	-.126	-.554
Positive affect x Meaning in life	.006	.031
Negative affect x Meaning in life	.231	1.098
Life satisfaction x Meaning in life	.135	.550
Hopelessness x Locus of control	-.602	-1.387
Anxiety x Locus of control	-.173	-.336
Depression x Locus of control	.221	.658
Positive affect x Locus of control	.677	2.295*
Negative affect x Locus of control	.449	.628
Life satisfaction x Locus of control	-.103	-.225
Hopelessness x Health locus of control	.003	.009
Anxiety x Health locus of control	-.316	-.839
Depression x Health locus of control	.250	.612
Positive affect x Health locus of control	.208	.894
Negative affect x Health locus of control	.209	.495
Life satisfaction x Health locus of control	.198	.744
Hopelessness x Optimism	-.584	-2.608*
Anxiety x Optimism	-.248	-.619
Depression x Optimism	.127	.418
Positive affect x Optimism	.521	2.124*
Negative affect x Optimism	.409	.766
Life satisfaction x Optimism	-.078	-.242
(Adj. R^2 = .54, F = 2.99**)		
(R^2 chg F = 3.09**)		

* $p < .05$, ** $p < .01$

On the first step, the adjusted R^2 for the main effects is not significant. On the second step, with the addition of the interaction effects, the adjusted R^2 becomes significant. The R^2-change is also significant. Four interaction effects predict impairment status: anxiety x meaning in life, positive affect x locus of control, hopelessness x optimism, and positive affect x optimism. Of the four, positive affect x locus of control is marginally the strongest predictor. The combined variables account for a large amount of the variance in impairment status.

The four interactions were interpreted with subgroup analyses using median splits on meaning in life, locus of control, and optimism. An inspection of the anxiety x meaning in life interaction indicated that anxiety impacts on impairment status more strongly if meaning in life is weaker (B = .076) than if meaning in life is stronger (B = -.005). For people with weaker meaning, as anxiety increases, impairment worsens. For people with stronger meaning, as anxiety increases, impairment stays the same.

An inspection of the positive affect x locus of control interaction revealed that positive affect impacts on impairment status more strongly if locus of control is external (B = .084) than if locus of control is internal (B = -.022). For people with an external LOC, as positive affect increases, impairment worsens. For people with an internal LOC, as positive affect increases, impairment improves.

A scrutiny of the positive affect x optimism interaction indicated that positive affect impacts on impairment status more strongly when optimism is stronger (B = .032) than when optimism is weaker (B = -.004). For more highly optimistic people, as positive affect increases, impairment worsens. For people with weaker optimism, as positive affect increases, impairment remains the same. This finding does not support the conceptual expectation that strong optimism will have a protective function on health outcomes.

Examination of the optimism x hopelessness interaction revealed that hopelessness impacts on impairment status more strongly when optimism is stronger (B = -.395) than when optimism is weaker (B = -.026). As hopelessness increases, impairment

improves, and this relation is stronger for more highly optimistic people.

In the second series of regressions, the physical health status variables, in turn, were again treated as dependent variables. The psychological well-being variables, the social support variables, and time were entered on step 1. The product terms, well-being x social support, were entered on step 2.

Again, only statistically significant ($p < .05$) findings are reported in the text. Other result tables can be found in Appendix H (Tables H-6 to H-10).

Self-rated health change (2)

The summary results of the multiple regression analysis, with self-rated health change as the dependent variable, are shown in Table 25.

Table 25. *Results for Self-rated Health Change Regressed on Well-being, Social Support and Time (N = 60)*

Variable	Beta	*t*
Main Effects		
Hopelessness	-.161	-1.159
Anxiety	-.360	-1.552
Depression	.300	1.525
Positive affect	.159	.988
Negative affect	-.068	-.326
Life satisfaction	-.090	-.552
Social support network	.061	.369
Social support satisfaction	-.006	-.037
Time	-.051	-.360
(Adj. R^2 = -.00, F =.99)		
Interaction Effects		
Hopelessness x Social support network	.070	.301
Anxiety x Social support network	.637	1.623
Depression x Social support network	-.744	-3.452**
Positive affect x Social support network	.221	.956
Negative affect x Social support network	-.075	-.203
Life satisfaction x Social support network	.186	.770
Hopelessness x Social support satisfaction	-.133	-.835
Anxiety x Social support satisfaction	-.294	-.894
Depression x Social support satisfaction	.464	1.811
Positive affect x Social support satisfaction	-.331	-1.665
Negative affect x Social support satisfaction	-.440	-1.771
Life satisfaction x Social support satisfaction	-.089	-.315
(Adj. R^2 = .23, F = 1.86*)		
(R^2 chg F = 2.28*)		

* $p <$ .05, ** $p <$ .01

On step 1, the adjusted R^2 for the main effects is not significant. The adjusted R^2, with the interaction effects added, becomes significant and a moderate amount of the variance in self-rated health change is explained. The R^2-change is also significant. Social support network x depression predicts self-rated health change.

To interpret the interaction, sub-group analyses using a median split (on social support

network) was performed. An examination of the interaction revealed that depression impacts on self-rated health change more strongly if social support network is smaller (B = .084) than if social support network is larger (B = .046). As depression increases, self-rated health improves. This relation is stronger for people with a smaller social support network. This is not a conceptually sensible finding, because self-rated health would be expected to worsen, as depression increases.

Impairment status (2)

The summary results of the multiple regression analysis, with impairment status as the outcome variable, is displayed in Table 26.

Table 26. *Results for Impairment Status Regressed on Well-being, Social Support and Time (N = 60)*

Variable	Beta	*t*
Main Effects		
Hopelessness	-.209	-1.519
Anxiety	.341	1.486
Depression	-.144	-.741
Positive affect	.071	.448
Negative affect	.015	.074
Life satisfaction	-.107	-.666
Social support network	-.092	-.564
Social support satisfaction	.024	.152
Time	.258	1.855
(Adj. R^2 = .02, F = 1.17)		
Interaction Effects		
Hopelessness x Social support network	-.098	-.457
Anxiety x Social support network	-.382	-1.050
Depression x Social support network	-.181	-.903
Positive affect x Social support network	-.304	-1.416
Negative affect x Social support network	.125	.367
Life satisfaction x Social support network	-.037	-.165
Hopelessness x Social support satisfaction	.407	2.763**
Anxiety x Social support satisfaction	.555	1.820
Depression x Social support satisfaction	.122	.515
Positive affect x Social support satisfaction	-.329	-1.785
Negative affect x Social support satisfaction	-.388	-1.684
Life satisfaction x Social support satisfaction	.289	1.102
(Adj. R^2 = .34, F = 2.46**)		
(R^2 chg F = 3.01**)		

* $p < .05$, ** $p < .01$

The adjusted R^2 for the main effects is not significant. After the interaction effects are added, the adjusted R^2 becomes significant and explains a moderate amount of the variance in impairment status. The R^2-change is also significant. Social support satisfaction x hopelessness predicts impairment status.

The interaction was interpreted with sub-group analyses using a median split on social

support satisfaction. An inspection of the social support satisfaction x hopelessness interaction indicated that hopelessness impacts on impairment status more strongly if social support satisfaction is weaker (B = -.357) than if social support satisfaction is stronger (B = -.014). As hopelessness increases, impairment improves. This relation is stronger for people with weaker social support satisfaction. The direction of this effect indicates an anomalous finding. It would be expected that as hopelessness increases, impairment worsens.

Neurologic dysfunction (2)

The summary results of the multiple regression analysis, with neurologic dysfunction as the dependent variable, is presented in Table 27.

Table 27. *Results for Neurologic Dysfunction Regressed on Well-being, Social Support and Time (N = 60)*

Variable	Beta	*t*
Main Effects		
Hopelessness	-.067	-.526
Anxiety	-.089	-.420
Depression	.239	1.325
Positive affect	-.068	-.465
Negative affect	-.161	-.847
Life satisfaction	-.164	-1.103
Social support network	-.013	-.085
Social support satisfaction	-.062	-.420
Time	.500	3.863**
(Adj. R^2 = .16, F = 2.23*)		
Interaction Effects		
Hopelessness x Social support network	-.034	-.126
Anxiety x Social support network	-.293	-.645
Depression x Social support network	.248	.996
Positive affect x Social support network	-.007	-.025
Negative affect x Social support network	.258	.608
Life satisfaction x Social support network	-.184	-.658
Hopelessness x Social support satisfaction	.125	.677
Anxiety x Social support satisfaction	.164	.432
Depression x Social support satisfaction	-.351	-1.182
Positive affect x Social support satisfaction	-.111	-.484
Negative affect x Social support satisfaction	-.020	-.068
Life satisfaction x Social support satisfaction	.157	.481
(Adj. R^2 = -.02, F = .93)		
(R^2 chg F = .26)		

* $p < .05$, ** $p < .01$

The adjusted R^2 for the main effects is significant, accounting for a small proportion of the variance in neurologic function. Time (t = 3.863, $p < .01$) predicts functional systems, and as expected, has a positive relation. On the second step, with the addition of the interaction effects, the adjusted R^2 is not significant.

Summary

The results of these regressions provide some support for the theoretical model. The findings suggest that disposition and social support moderate how changes in well-being relate to changes in health status. The findings also provide limited evidence to suggest that changes in well-being directly influence changes in health status. Although there were several significant moderating effects, the effects were not always in line with conceptual expectations.

It is of interest that time related to changes in neurologic dysfunction. This indicates that the trend of time has a linear relation to neurologic dysfunction; as time goes on, neurologic dysfunction increases.

Overall the pattern of results from the within-subject regressions differ from those of the between-subject regressions. In the between-subject analyses, neither disposition nor social support moderated the impact of emotional states on health outcomes, whereas, in the within-subject regressions, these factors emerged as moderators of emotional states. This suggests that disposition and social support may function as moderators of emotional states on physical health only when considered within a change context. These relations will be explored further at the individual case level in the next chapter.

Determinants of stressors

Standard within-subject multiple regression analysis was utilised to test the hypothesis that changes in physical health status relate to changes in stressors. Hassles and life events were the dependent variables in turn. Health change, disability (ADL), symptom frequency, symptom intensity, other-rated health, impairment status, disability (FIM) and neurologic dysfunction were the independent variables, entered together.

When predicting hassles, the adjusted R^2 of .15 is significant, $F(9,50) = 2.14, p < .05$, accounting for a small proportion of the variance. Both self-rated health change ($t = 2.145, p < .05$) and symptom intensity ($t = 2.168, p < .05$) predict hassles. The beta

weights indicate that self-rated health change is a marginally stronger predictor of hassles. As expected, both symptom intensity and self-rated health change have a positive relation to hassles. With life events as the dependent variable, the adjusted R^2 of .06 is not significant, $F(9,50) = .73$, ns. The findings provide evidence to suggest that changes in health status are related to changes in chronic everyday stressors, but are not associated with changes in major life events.

CONCLUSION

In the theoretical model, changes in stressors, psychological well-being and health status are proposed to relate to one another over time. The more stable factors of disposition and social support are viewed as contributing to changes in well-being, as well as moderating the impact of stressors on well-being, and the impact of well-being on health status. Table 28 presents a summary of the significant findings. The findings suggest that disposition and social support moderate how changes in stressors relate to changes in well-being, and how changes in well-being relate to changes in health status. However, in many instances, the interpretation of the interaction effect did not support the conceptual expectation, and these discrepancies will be considered in the Discussion and Conclusion chapter. The findings also suggest that changes in health status are associated with changes in chronic everyday stressors (hassles).

Table 28. *Summary of Significant Within-subject Multiple Regression Results*

Independent variable	Dependent variable
Determinants of psychological well-being	
Hassles x Locus of control	Hopelessness
Life events x Locus of control	Hopelessness
Life events x Health locus of control	Hopelessness
Hassles x Meaning in life	Life satisfaction
Life events x Optimism	Life satisfaction
Life events x Social support network	Life satisfaction
Determinants of physical health status	
Positive affect	Disability (ADL)
Time	Neurologic dysfunction
Positive affect x Health locus of control	Self-rated health change
Depression x Social support network	Self-rated health change
Anxiety x Meaning in life	Impairment status
Positive affect x Locus of control	Impairment status
Hopelessness x Optimism	Impairment status
Positive affect x Optimism	Impairment status
Hopelessness x Social support satisfaction	Impairment status
Determinants of stressors	
Self-rated health change	Hassles
Symptom intensity	Hassles

The pattern of the within-subject findings differ from the between-subject findings. The most striking difference concerns the way in which effects are exerted on outcome variables. In the between-subject group, there is an absence of moderating effects. In the within-subject group, although there are fewer significant effects overall, there are several significant moderating effects. This suggests that variables take on a different role depending on whether they are considered in a static or change context. Although, it is also feasible that the increase in interaction effects is a reflection of the larger *N*.

Overall, support for the model is mixed, with some relations appearing more promising than others. In the next chapter, the significant relationships will be explored in more detail, at an individual case level, to gain a fuller understanding of how psychosocial and physical health factors relate during the course of multiple sclerosis.

CHAPTER 7

INDIVIDUAL RESPONSE PATTERNS

This chapter, like the previous chapter, concentrates on data collected during the longitudinal phase of the study from 12 participants. However, the way in which the data is analyzed and interpreted provides an entirely different focus. The previous chapter was concerned with relations among the variables in the model, revealing patterns in the data for the group as a whole. The analyses used averaged scores (means and correlations), providing information on general patterns, but hiding levels, variability and covariability of variables for individuals. Further, although time was considered in general terms, no references were made to specific time points. With this type of approach used exclusively, valuable information about the person can be lost. Further, research has suggested that MS patients are very diverse in their psychological responses to their illness (Peyser et al., 1980; Zeldow & Pavlou, 1988).

The present chapter aims to examine, at an individual case level, how a particular variable (or variables) changes over time. When two or more variables are involved, the focus is on how the variables change, relative to one another. The secondary aim is to investigate how the variables in the theoretical model relate to one another; examining changes at the individual level over a seven month period. These aims are best accomplished by using a descriptive, non-statistical approach. It was impossible to explore all associations between variables for each individual, therefore relations which appeared promising, based on significant within-subject results presented in the previous chapter, are explored in more detail. Dispositional and social support variables, assessed only twice, are not considered in terms of change over time, however, their role as moderating variables are examined.

Raw scores are used when examining levels, variability and trends of individual variables. *Z*-scores, created around individual means, are used when comparing variables that are based on different scales. Raw scores and *Z*-scores for each variable,

on a case by case basis, are provided in Appendix I (Tables I-1 to I-7). Throughout the text, data patterns are illustrated by highlighting specific cases, and on occasion graphs are used to depict notable associations among the variables. To assist with the interpretation of the data, contextual information about people's lives, collected during the interviews, is provided. Where appropriate, personal circumstances are discussed or recent life events are mentioned. In some instances item content is examined to gain a clearer understanding of the individual's experience.

SINGLE VARIABLE AND CONSTRUCT PATTERNS

For each person, stressor variables, psychological well-being variables, and physical health status variables were examined in turn. When investigating single variables, scores at each time point were graphed, case by case. To explore data patterns an inspection was made of levels; the relative degree of a variable, from high to low, and variability; fluctuations that occur in a variable over time. Trends, the tendency of variables to follow an upward or downward direction over time, were, because of the deteriorating nature of MS, relevant for physical health status variables; although changes may not necessarily occur during the short time frame of this study. Considering trends for the other constructs is less appropriate from a conceptual perspective and in light of the arbitrary time frame of this study, where people became participants during varying stages of their MS illness.

Stressor variables

The two stressor variables, hassles and life events were examined for each person. Scores for each person at each time are provided in Appendix I (Table I-1), page 293. For people suffering from a chronic illness, the level of stressors, particularly minor daily hassles, might be expected to be high. Multiple high life events might also be anticipated if consideration is given to health related events such as admissions to hospital and surgery. On the other hand, people with MS would probably change jobs less frequently (most are not working) and shift house less often, (many modify their houses) and so on.

Hassles were generally reported at low levels. Out of a possible score of 159, most people's scores are consistently under 30. Although these scores seem quite low, they are in line with the larger cross-sectional group mean score for hassles (M = 21) (refer to chapter 5). Furthermore, they are slightly higher than within-subject daily hassles mean scores (M = 16.26) for a sample of married couples (DeLongis et al., 1988). The common response pattern for hassles is illustrated by the individual in case 8. Hassles are at a low level and fluctuate slightly from month to month.

One person (case 6) reported a consistently moderate level of hassles. The items she endorsed revealed ongoing strong concerns about financial matters. For most people, hassles demonstrate moderate variability; they fluctuate somewhat from month to month, but remain basically at the same level. In an exceptional instance (case 10), a person's reported hassles show little variability in the first six months, but increase considerably in the seventh month. An examination of the items this person endorsed shows an increase in hassles across all areas, rather than concerns in specific domains.

Reports of recent life events varied considerably, from low to high levels, and show low to moderate variability. There is not a single case where life events were not reported at some time during the seven months of the study. The majority of cases are at a low level (scores under 4), relative to the maximum score of 9. However, this may be misleading given that even reporting a single life event can mean something major has happened in a person's life. This common pattern, showing inconsistent life events that occur at low levels, is illustrated by the person in case 9.

Two people reported high life events (7 or over) for a particular month. In one instance (case 10), at time 4, the person experienced the death of two close friends, a major increase in pain associated with MS, and her sister shifting to Auckland (they previously lived together). In the other instance (case 12), at time 4, the person reported preparation for shifting houses, beginning a new job, and her husband going away for a business trip.

Stressor construct

For the vast majority of people, hassles and life events have no obvious relation to one another. An example of a typical profile can be seen in Figure 3.

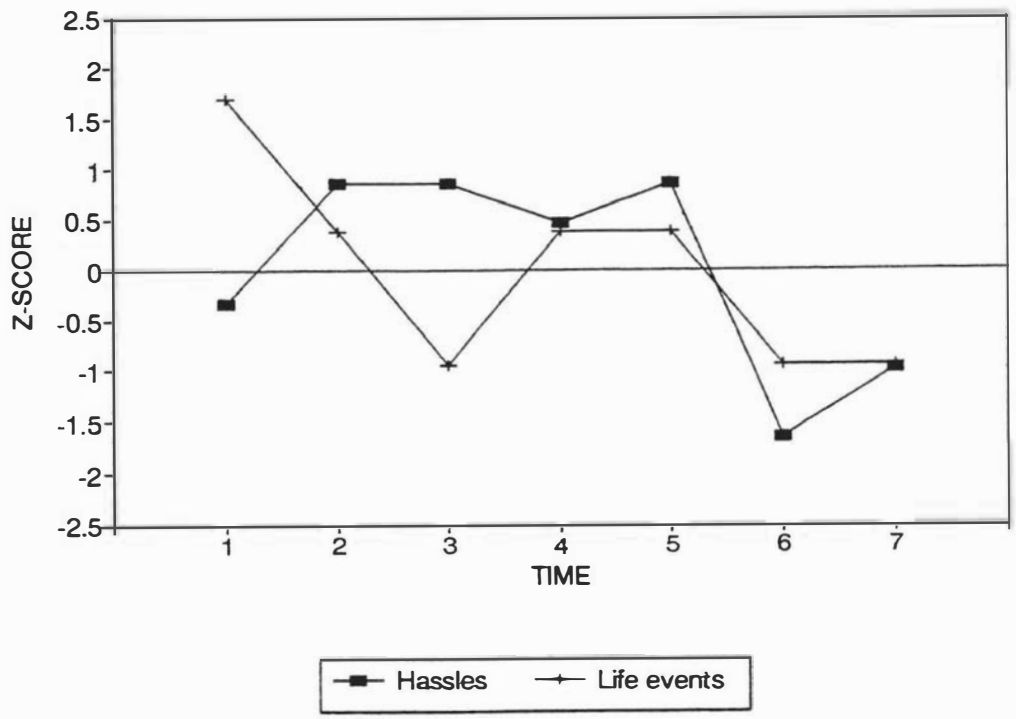


Figure 3. Intraindividual changes in hassles and life events over seven months (case 2).

For one person, as life events increase, hassles decrease, and conversely, as hassles increase life events decrease. This unusual relation is displayed in Figure 4. An examination of the items at times 4 and 5, when hassles and life events showed the most pronounced difference, did not suggest an explanation.

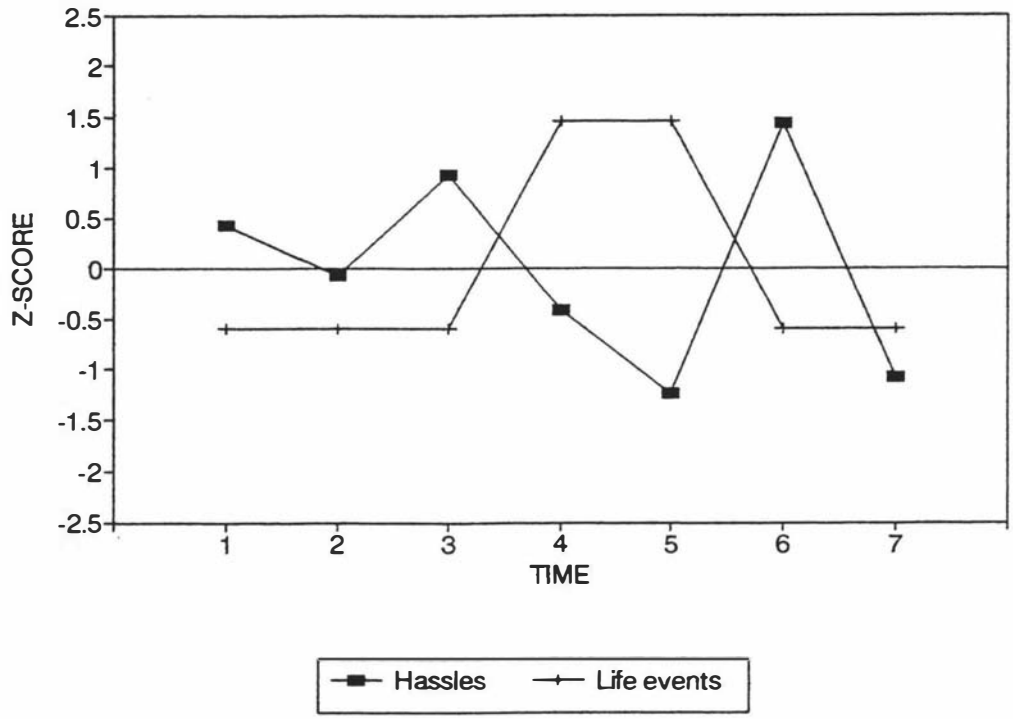


Figure 4. Intraindividual changes in hassles and life events over seven months (case 8).

Psychological well-being variables

This study included four negative and two positive well-being variables: hopelessness, depression, anxiety, negative affect, positive affect and life satisfaction. Scores for each person at each time are presented in Appendix I (Tables I-2 & I-3), pages 294 to 296. People with MS are usually regarded as having worse psychological well-being than healthy people. Evidence of hopelessness, depression, anxiety and negative affect, and conversely, diminished positive affect and lowered life satisfaction, might be expected.

Turning to the negative well-being variables, hopelessness generally demonstrates very low levels, and little variability. Scores can vary from a minimum of 8 to a maximum of 16. In many cases scores are 8, and overall, scores are in the 8 to 11 range. This appears low, but is consistent with the larger cross-sectional group mean for hopelessness (M = 9.24, refer to chapter 5). There is a notable exception. One person (case 6) reported strong hopelessness at time 7. Her giving up response was preceded by a number of factors. During that month she experienced a death in her family and

had three serious falls, one causing an injury. She was advised to have handrails installed on her steps, an indication of worsening MS.

Depression levels vary from low to moderate. Possible scores on this scale can range from between 4 and 23. Three people appear to have no or mild depression (scores consistently under 11); the other nine appear to experience moderate depression. However, because the depression scale is not a clinical instrument, scores can only intimate the degree of depression experienced. Moderate variability is present; certainly more than was found in hopelessness. A consistently low level of depression is illustrated by the individual in case 3, and a moderate level of depression is illustrated by the person in case 7.

As with depression, anxiety also demonstrates low to moderate levels, and low to moderate variability. Possible scores can vary from 8 to 45. Eight people appear to have no or mild anxiety (scores consistently under 25), and the other four appear to experience moderate anxiety. Once again scores are only suggestive of the degree of anxiety experienced, because a clinical scale was not utilised. The person in case 12 exemplifies the typical low anxiety profile, and the individual in case 6 illustrates the typical moderate anxiety profile.

Similar to depression and anxiety, negative affect is mainly at low to moderate levels, and shows low to moderate variability. Although scores can range from between 10 and 50, most people's scores fell between 10 and 30. The common response pattern for negative affect, with low levels and very small fluctuations from month to month, is illustrated by the person in case 2. In previous research (Watson, Clark & Tellegen, 1988), when using primarily university students, negative affect was reported at comparable levels (M = 19.5). In the present study, two people (cases 6 & 11) reported exceptionally high negative affect. However, the high level of negative emotion was not consistent over time for either of these individuals. To try to understand what these people were experiencing when negative affect crested, item content and personal circumstances were examined. For one person (case 6), every negative adjective was strongly endorsed, except *guilty* and *hostile*. At the time, he was

experiencing severe back pain from sciatic nerve damage. It was unknown whether this was a consequence of MS activity, but regardless, it made his MS symptoms and signs appear worse. The other person (case 11) gave strong endorsements to all negative adjectives except *irritable* and *nervous*. This woman had recently been through the traumatic experience of being raped. She was taking medication for depression, until time 3, when medication was discontinued. (Her level of depression fell rapidly between time 1 and 3, while she was taking the medication.) The elevation of negative affect at time 5 coincides with admission to the hospital, where she received treatment for a severe urinary infection.

Now examining the positive well-being variables, positive affect occurs at low to high levels, with most people reporting a moderate level. Little variability in positive affect occurs for the majority of people. In cases where fluctuations do ensue, they tend to be temporary, with people returning to their own base level. Scores can vary from 10 to 50. Most people's scores are in the 25 to 40 range. This is similar to levels of positive affect reported for university students (M = 32)(Watson et al., 1988). Case 9 is an example of a person experiencing consistently low positive affect, with scores ranging from around 20 to 25. In contrast, case 11 is an example of a person experiencing consistently high positive affect, with scores ranging from 40 to 50. It is interesting that, in most months, this woman endorsed both positive and negative affect items at intense levels. She appears to be very passionate in her emotional feelings. The positive affect items she endorsed were extensive, with *proud*, *determined* and *interested*, assigned the most consistent and intense ratings.

Life satisfaction is present at moderate to high levels, and in most cases, shows little variability. Scores can vary between 2 and 14. For the majority of people, scores are in the 8 to 12 range. The person in case 7 illustrates this common profile, where scores are at a moderate level and do not vary markedly from month to month. Levels of life satisfaction reported here, are similar to those found in other studies, focusing on different groups: mothers (M = 10.4) and elderly people (M = 10.5) (Chamberlain & Zika, 1989). The individual in case 5 illustrates a more unusual profile, where life satisfaction is basically high, but drops dramatically at time 4. As this is not a common

pattern, the person's circumstances were examined. At time 4, the woman was in substantial distress about her financial situation. Although she was married, her husband's salary was insufficient, and after the bills were paid, little was left over for recreation. The two activities the woman valued most were swimming and riding on her specially adapted scooter. The battery on her scooter was flat and needed replacing. During the month, there had neither been money for pool entrance fees, nor money for a new battery. Consequently, she had been housebound all month. In the following month, an extended family member offered her a small amount of money each month, to allow her to pursue her favourite activities. At this time, her life satisfaction returned to its former high level. It is interesting to note that the woman had no changes in physical health throughout this period.

Psychological well-being construct

The large number of psychological well-being variables made it difficult to examine all construct variables together. Therefore, it was conceptually sensibly to examine negative well-being variables and positive well-being variables separately. First consideration was given to the negative well-being variables. Most people tend to experience changes in negative affect, anxiety and depression concurrently. Figure 5 shows this pattern. Hopelessness, in contrast, appears to function more separately and out of step with the other variables. In a few cases it parallels the other negative well-being measures, but in most cases it displays no obvious association with the other variables. Clearly, hopelessness does not demonstrate the degree of variability found in the other variables. For a few people, an increase in hopelessness appears to precede a rise in the other negative well-being variables. This pattern is illustrated in Figure 6. Overall, it is apparent that negative affect, anxiety, and depression are representing a common negative well-being dimension, whereas, hopelessness appears to be less of a core variable. This may be a consequence of assessing only one dimension of hopelessness, (giving up response). Alternatively it is possible that negative affect, anxiety and depression require primarily emotional assessments, in contrast to a dimension of hopelessness which demands a more cognitive appraisal.

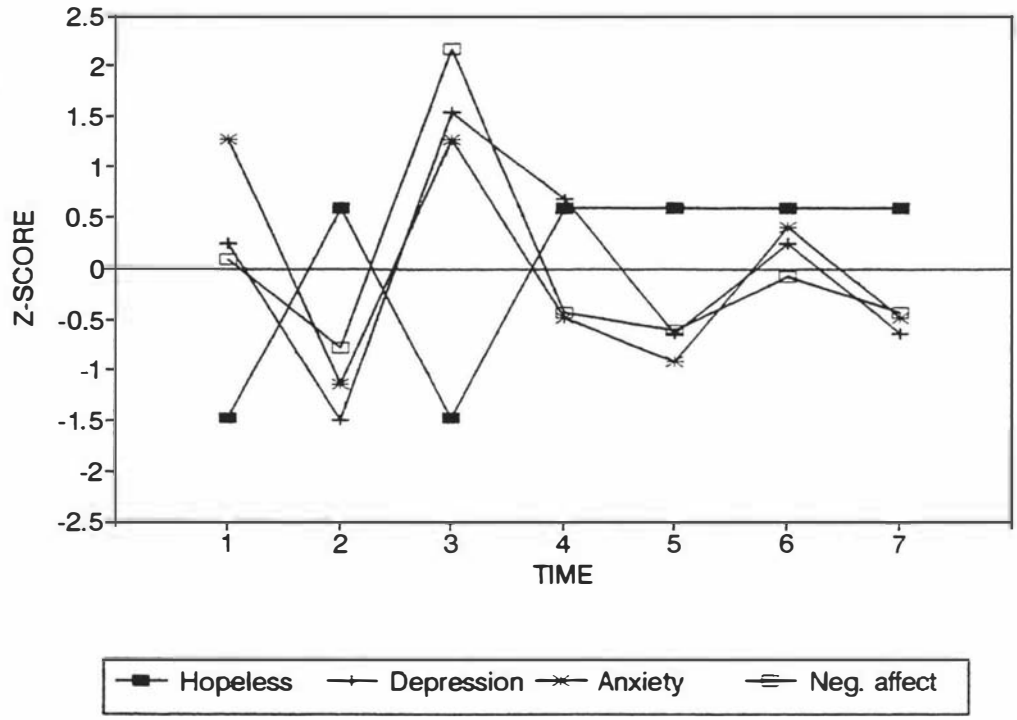


Figure 5. Intraindividual changes in hopelessness, depression, anxiety and negative affect over seven months (case 1).

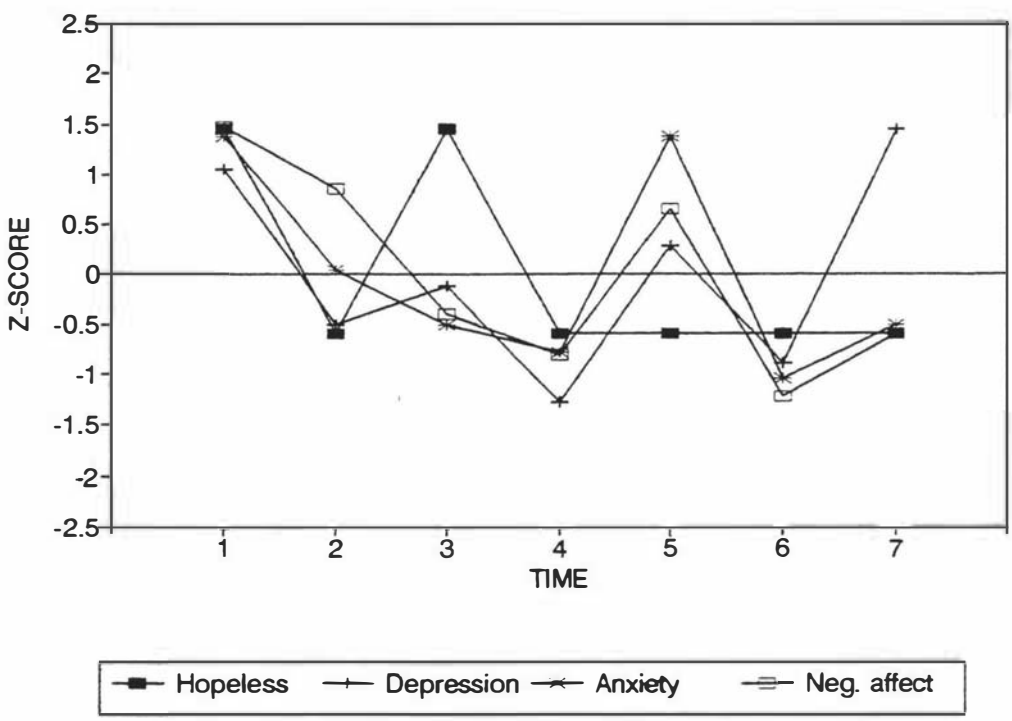


Figure 6. Intraindividual changes in hopelessness, depression, anxiety and negative affect over seven months (case 11).

Next, the positive well-being variables, positive affect and life satisfaction, were examined. In five cases, positive affect and life satisfaction increase and decrease in accord with one another. For these people, positive affect and life satisfaction increase and decrease simultaneously. Figure 7 is an example of this association. However, the majority of people appear to experience positive affect and life satisfaction as quite separate states. This association is illustrated in Figure 8. It is surprising that the two positive well-being variables do not change in unison, given that they both represent aspects of people's happiness and satisfaction in life. However, this may be partially explained by their conceptual difference. Positive affect is primarily an emotional assessment and in contrast, life satisfaction is largely a cognitive appraisal (Chamberlain, 1988).

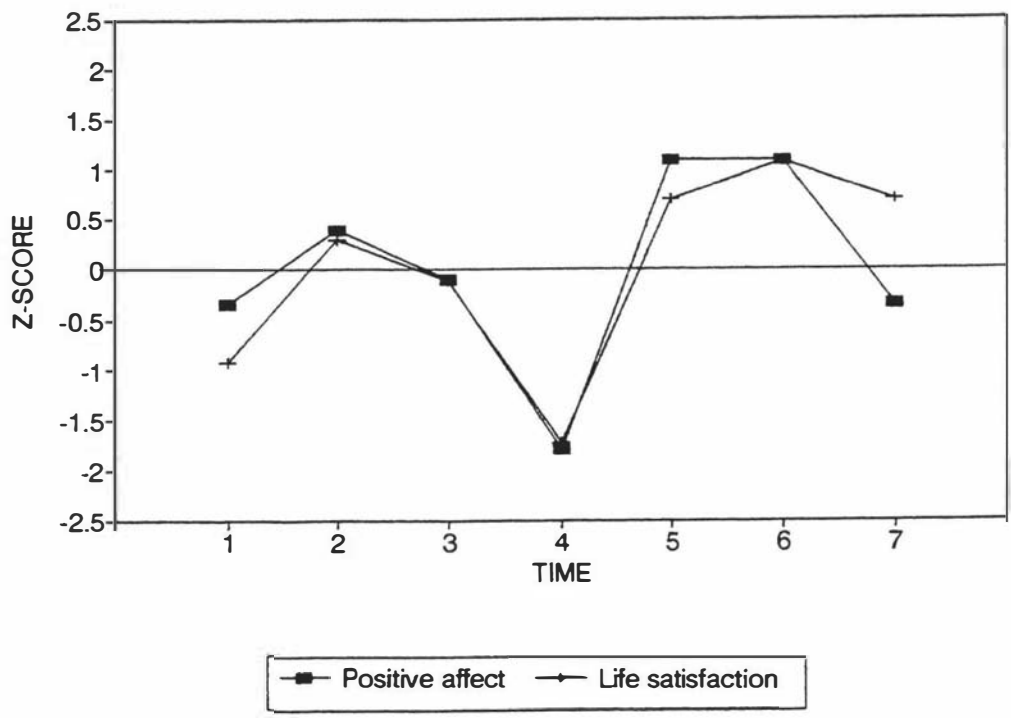


Figure 7. Intraindividual changes in positive affect and life satisfaction over seven months (case 5).

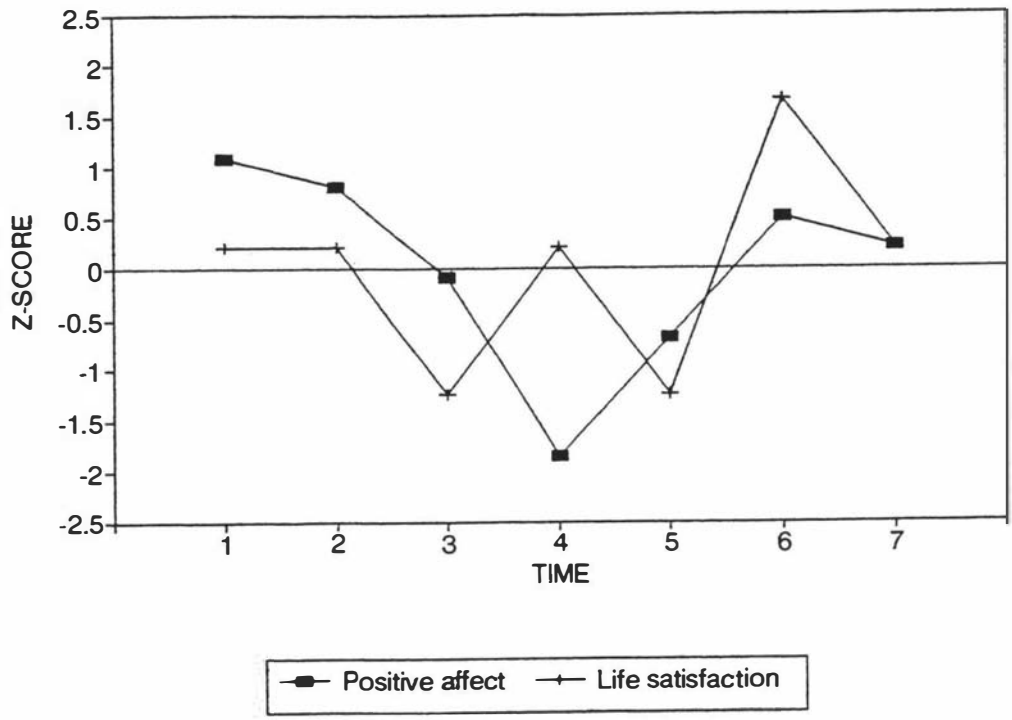


Figure 8. Intraindividual changes in positive affect and life satisfaction over seven months (case 7).

Physical health status variables

The eight health status variables encompass four health constructs: MS symptoms (intensity and frequency), disability (functional independence and activity of daily living), impairment (impairment status and neurologic dysfunction) and general health (self-rated health change and other-rated health change). All variables were measured seven times with the exception of those collected during the physical examinations. Disability (ADL), impairment status and neurologic dysfunction, were assessed at six points (T2 to T7), and other-rated health change, was assessed at five points (T3 to T7). (For more details refer to Method chapter). Scores for each person at each time are provided in Appendix I (Tables I-4 to I-7), pages 297 to 300.

Differences in health would be expected among the participants in this study, who have experienced MS for varying lengths of time and have either mild, moderate or severe MS. Earlier, it was mentioned that to some extent a downward trend in certain aspects

of health might be anticipated for some individuals. Most people with MS experience gradual deterioration in health over time, with the rate of decline varying for every person. For some individuals, MS may plateau and remain stable for weeks, months or years.

The large number of health status variables made it advisable to examine the variables in two clusters. Placement of variables into a group was determined by their conceptual relationship to one another. It seemed likely that changes in MS symptoms would be accompanied by more general changes in health. Therefore, the two MS symptom variables (intensity and frequency), and the two health change variables (self-rated and other-rated) were included in one group. It was anticipated that changes in impairment would be linked to changes in disability. Hence, the two disability variables (FIM and ADL) and the two impairment variables (impairment status and neurologic dysfunction) comprised the other group.

In this sample, comprising people whose MS is at different stages, it would be expected that at least a few people would report numerous and intense MS symptoms, and that a few would report few and mild symptoms. Symptom intensity shows low to high levels, moderate variability, and no trend. The majority of people reported the intensity of their symptoms to be in the low to moderate realm, with scores between 10 and 80, out of a possible 0 to 120 range. The person in case 10 illustrates a common profile. This woman reported experiencing a few intense symptoms: weakness, fatigue, and numbness. The other symptoms were either not present, or they were not very intense. A few people reported consistently intense symptoms. An example of this pattern is illustrated by the individual in case 6. This woman had severe and advanced MS. She consistently reported numerous intense symptoms: balance problems, spasticity, tremors, weakness, fatigue, visual disturbances, numbness, bladder problems, bowel problems, and pain.

Symptom frequency demonstrates moderate to high levels, low to moderate variability, and no trend. Possible scores could vary between 12 and 60. About half the people scored in the 20 to 40 range, and the other half scored in the 30 to 50 range. The

person in case 1 demonstrates a typical profile, with symptom frequency at a consistently moderate level. In contrast, two people (cases 11 & 12) had scores consistently over 40, which indicates very frequent symptoms. Both these people had severe MS and reported numerous symptoms to be constantly present.

Self-rated health change and other-rated health change are at moderate levels, demonstrate low to moderate variability, and show no trend. Self-rated health change and other-rated health change, in every case, follow a very similar pattern. This indicates that people perceive changes in their overall health similarly to the way in which the physician viewed them.

In this sample, some people would be expected to experience difficulty dealing with their daily activities, showing higher levels of disability. Other people would probably be unaffected in their ability to carry out normal daily tasks. The two disability variables, FIM and ADL, both generally show no trends, high levels of ability, and almost no variability. FIM scores can range from 21 to 126. Most people have scores that are consistently over 115. The person in case 4 demonstrates an unusual case, where both lower scores and greater variability is present. It is interesting to consider personal circumstances that may have contributed to this unusual profile. The man, who suffered from severe MS, had been living in the local hospital for several months prior to his assessment at time 2, but was still able to care for most of his personal needs. At time 3, he was transferred to a hospital in a different city for major reconstructive surgery. This was necessary following a severe infection (originating from a pressure sore) that had destroyed a large amount of the body tissue on his buttocks. During his initial recovery, at time 3, he was confined to bed (lying on his stomach), and unable to do almost anything for himself. At time 4, he was transferred back to the local hospital, and after a short period in a recovery ward, he was placed in the Rehabilitation Unit. From that time he was in active rehabilitation, and a gradual increase in self care took place. These events correspond closely to his disability profile.

Among the participants in this study, impairment would be expected to vary from severe to mild. The impairment variables, impairment status and neurologic dysfunction both

demonstrate low to high levels, and little variability. The lack of variability was foreseen, because the nature of MS is a gradually deteriorating condition, and therefore, continual fluctuations in impairment would not be expected. A few people show a gradual downward trend in impairment status, and five people, demonstrate a gradual downward trend in neurologic dysfunction systems. However, for most people, impairment status and neurologic dysfunction are stable over the seven month period.

Physical health status construct

Symptom frequency and symptom intensity, for the vast majority of people, increase and decrease simultaneously. For some people, as expected, when symptom frequency and intensity increase, there is a corresponding drop in overall health; and as symptoms decrease, health improves. This association can be seen in Figure 9. However, for one person, overall health is static, although symptoms are in flux. Figure 10 illustrates this relationship. This man generally experienced a number of symptoms concurrently: balance problems, tremor, weakness, fatigue, spasticity and bladder problems. Although they varied in frequency and intensity from month to month, they apparently did not affect his rating of overall health change.

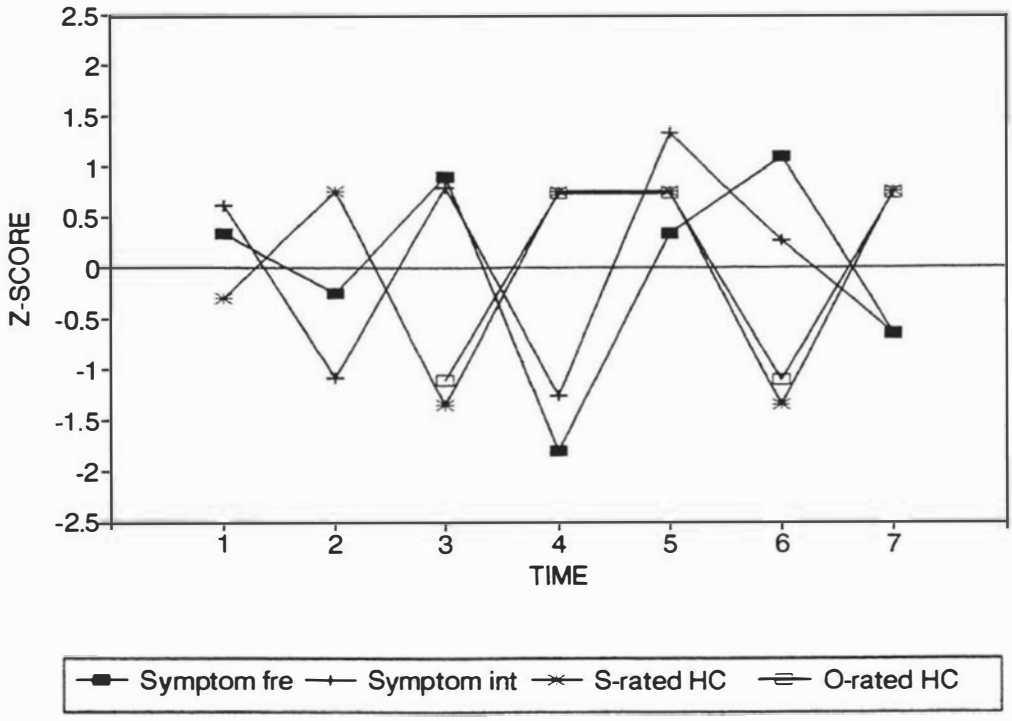


Figure 9. Intraindividual changes in symptom frequency, symptom intensity, self-rated health change and other-rated health change over seven months (case 1).

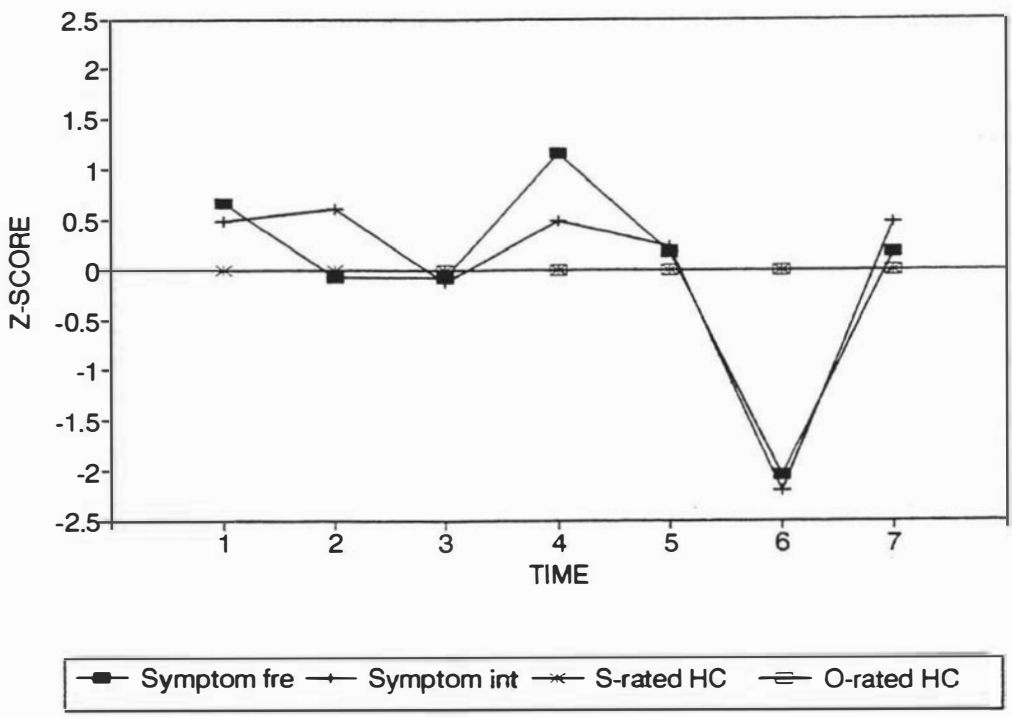


Figure 10. Intraindividual changes in symptom frequency, symptom intensity, self-rated health change and other-rated health change over seven months (case 3).

The disability variables, FIM and ADL, surprisingly, do not change together. This was not anticipated, because ADL and FIM both assess the degree to which people are able to care for themselves and perform simple daily tasks. The dissimilarity may be explained, in part, by the content of the measures, which differ to some extent in terms of activities evaluated. In addition, the data was collected in different ways; the ADL was self-assessed and the FIM was physician assessed. On both the FIM and the ADL, for the majority of people, scores do not tend to fluctuate, which supports the conceptual view of disability as a relatively stable factor over this time frame.

The relationship of the disability variables to the impairment variables is not clear. This is due in part to the differences in the way the disability variables change in relation to one another. Generally FIM displays a more conceptually congruent relationship with the impairment variables. As people's impairment increases, their disability worsens. This pattern which is evident in about half the cases, is illustrated in Figure 11. In a few people, neurologic dysfunction increases but disability remains stable. For these individuals, though some physical deterioration is evident, they may be able to compensate (perhaps doing the task more slowly) and therefore the decline is not reflected in their performance.

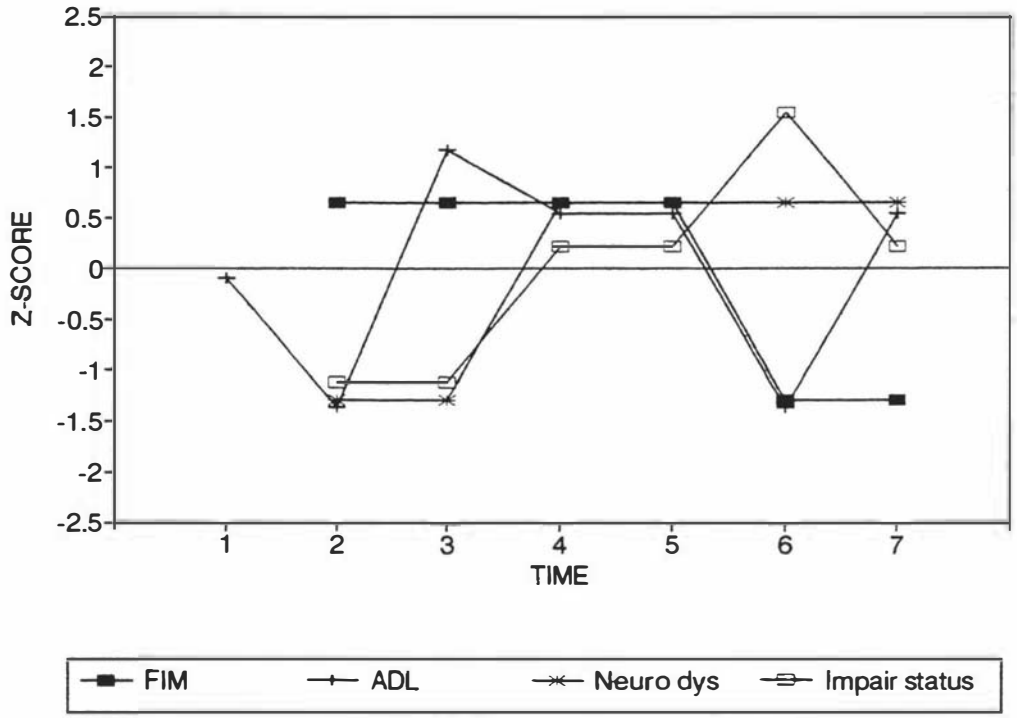


Figure 11. Intraindividual changes in disability (FIM), disability (ADL), neurologic dysfunction and impairment status over seven months (case 6).

SUMMARY

Although many stressors might be expected in people suffering from a chronic illness, most people reported surprisingly few hassles. For the majority of people, changes in life events did not parallel changes in hassles. Rather, hassles and life events appeared to have no specific relationship.

In terms of psychological well-being, most people appeared not to be hopeless, despite the fact that MS is incurable, and can be very debilitating. Hopelessness did not change in line with depression, anxiety and negative affect, suggesting that it is not a core feature of negative well-being. For the majority of people, changes in positive affect were not related to changes in life satisfaction.

Turning to health status, for most people, as symptoms became more frequent, they also tended to be more intense. For several individuals, as symptoms increased in

frequency and intensity, ratings of overall health changed for the worse. Conversely, as symptoms improved, ratings of overall health changed for the better. People were inclined to report changes in their overall health very similarly to the ratings provided by the physician. Level of impairment, as anticipated, did not change much over time, although for some people, a gradual worsening of impairment was evident. Disability, assessed in terms of daily activities, was unexpectedly mild. Even people with quite severe health problems were able to perform most everyday tasks. Unexpectedly, the two disability variables, FIM and ADL, did not change together, though they assess a similar construct.

Overall, the variables within the constructs of the model related in some predictable and some unpredictable ways. Although, there were a few unexpected patterns, on the whole, the findings support the conceptual underpinnings of the constructs. In the discussion chapter these issues will be considered in greater depth.

BETWEEN CONSTRUCT PATTERNS

In the previous chapter, significant results from within-subject analyses highlighted some relationships among the variables that warranted further investigation. Although a few of the relations were direct, the vast majority were interactive.

In this section, variable associations, both interactive and direct, are explored at the individual case level. This is important because the within-subject findings reflect an averaged response pattern, but do not reveal individual responses. The complete picture cannot be understood by considering only summary effects. A different pattern of findings may emerge when examined at the case level.

In order to examine the interactions, median splits were performed on moderating variables, and cases were assigned into high and low groups, with six people in each.

Determinants of psychological well-being

First, the findings from the within-subject analyses related to well-being were considered. Most significant findings involved interaction effects. When viewing these findings at an individual level, few of the interactions showed distinct patterns. Those that did will be discussed here.

In the regression analysis (p. 122) higher levels of hassles were related to greater hopelessness for people with a more external LOC orientation. For internal people, as hassles increased, hopelessness did not change. When examining individual cases, the findings are quite different. For externally orientated people there is no consistent pattern. Higher levels of hassles are related to less hopelessness for internally orientated people. Figure 12 illustrates this unexpected association. Unlike the within-subject findings, individual patterns are clearly contrary to conceptual expectations. This is a good example of a relation which appeared sensible when interpreted from summary effects, but which did not apply to any individual.

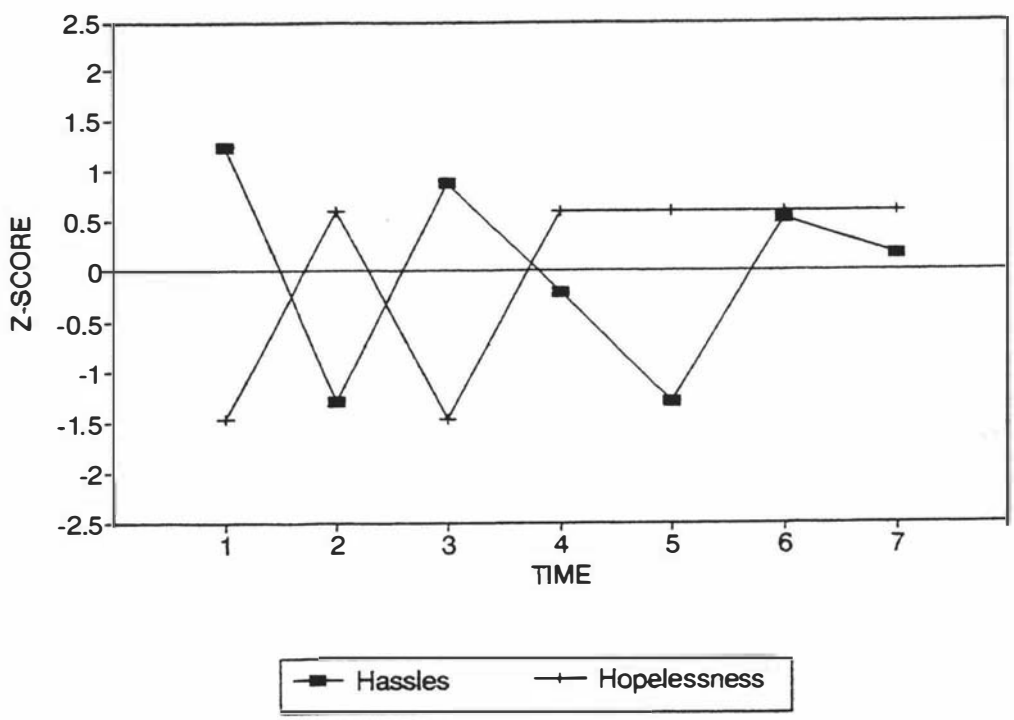


Figure 12. Intraindividual changes in hassles and hopelessness over seven months, for a person with an internal locus of control orientation (case 1).

In the regression analysis (p. 125) higher levels of hassles were related to poorer life satisfaction for people with stronger life meaning. For people with weaker meaning, as hassles increased, life satisfaction improved. A similar pattern emerges when examining individual cases. For most people with stronger meaning, higher levels of hassles are associated with poorer life satisfaction. It is notable that the relation was identical both when interpreted from summary effects and from individual patterns. This gives strong credibility to the relation, which is depicted in Figure 13. Dissimilar to the within-subject findings, no clear pattern emerges for people with weaker life meaning. From a conceptual point of view, it is puzzling why strong meaning does not function as a buffer against the impact of stressors on life satisfaction.

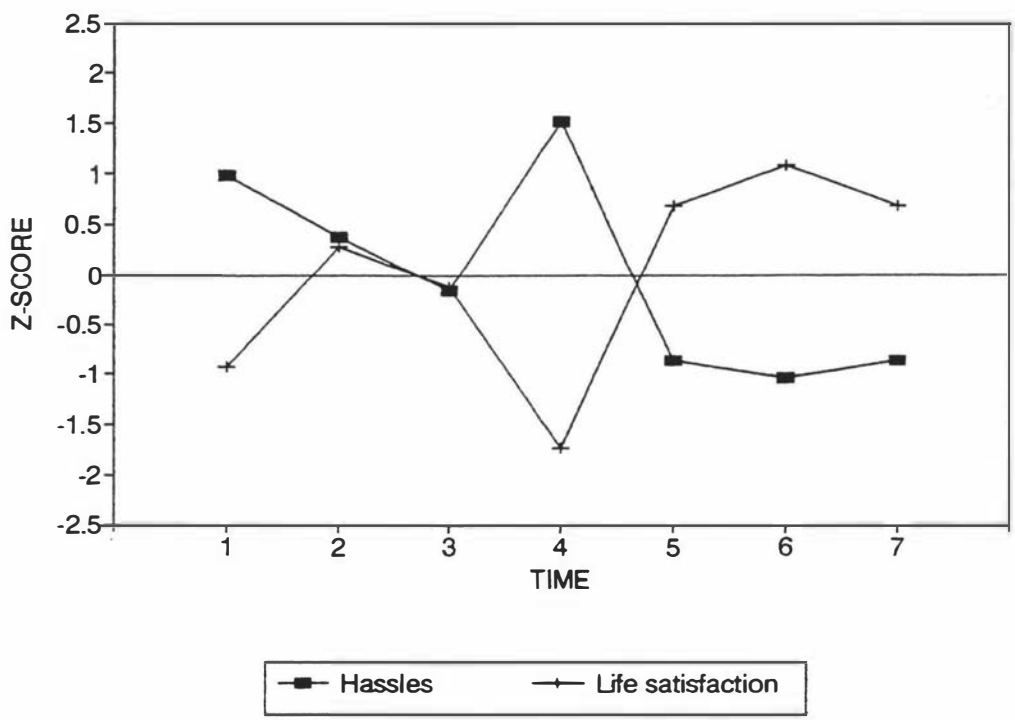


Figure 13. Intraindividual changes in hassles and life satisfaction over seven months, for a person with high meaning in life (case 5).

Determinants of physical health status

Next, the variables that were found in within-subject analyses to impact on physical

health status were considered. Again, most of the significant findings were interaction effects. Only interactions that revealed a distinct pattern at an individual level will be discussed here.

In the regression analysis (p. 133) increased anxiety was related to increased impairment for people with weaker life meaning. For people with stronger meaning, as anxiety increased, impairment improved. This interaction is striking because, as mentioned previously, impairment status is lacking in variability, making a significant association unlikely. In fact, seven out of twelve people, show no fluctuations in impairment status whatsoever. At the individual level, five out of six people with stronger life meaning show no variability in impairment. Therefore, little can be concluded about people with stronger life meaning in relation to the effects of anxiety. However, the association between meaning and impairment suggests that people with stronger meaning do not show as much deterioration in MS (over seven months) as people with weaker meaning. Or alternatively, people with MS who do not deteriorate quickly maintain stronger meaning. The pattern for people with weaker life meaning is similar to the within-subject finding. For most people, increased anxiety is related to increased impairment. Figure 14 shows this association. This is another important example of a relation supported from both summary effects and individual patterns.

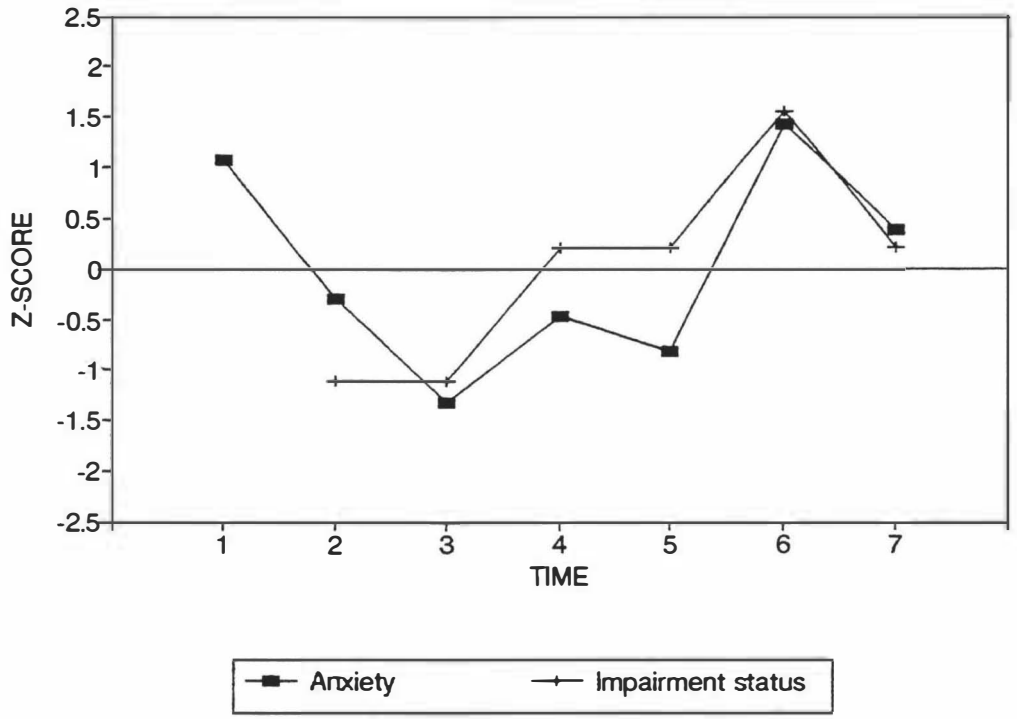


Figure 14. Intraindividual changes in anxiety and impairment status over seven months, for a person with low meaning in life (case 6).

In the within-subject analysis (p. 136) increased depression was related to improved self-rated health for people with a smaller support group. This pattern was the same for people with a larger support group, although to a lesser extent. This interpretation does not make conceptual sense. It would be anticipated that self-rated health would improve, as depression decreases, and that this effect would be stronger for people with a larger support group. This pattern is exactly what is revealed at the case level. For most people with a larger social support group, increased depression is associated with worsening self-rated health. Figure 15 illustrates this association. This is an excellent example of a finding which is not conceptually sensible at the averaged response level, but demonstrates appropriateness at the individual level. For people with a smaller social support group the patterns vary. For two people, depression increases as self-rated health worsens. For two people, depression increases as self-rated health improves. For the other individuals, no clear pattern of association is obvious.

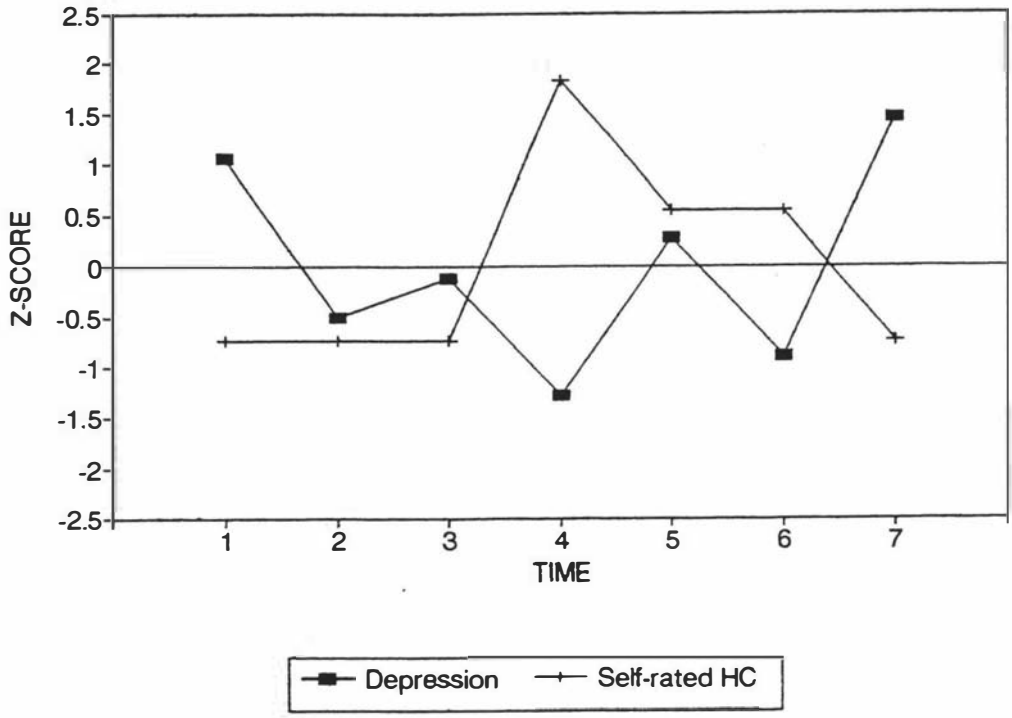


Figure 15. Intraindividual changes in depression and self-rated health change over seven months, for a person with a strong perceived social support (case 11).

Determinants of stressors

Finally, the variables that were found, in the within-subject analysis, to impact on stressors were considered. Self-rated health change and symptom intensity were both found to relate to hassles. At an individual level, a clear pattern is only evident in regard to the self-rated health and hassles relation. For most people, as health improves, hassles decrease; and conversely, as health worsens, hassles increase. This association is presented in Figure 16. Surprisingly, for a few people, hassles increase as health changes for the better, and decrease as health changes for the worse. Figure 17 displays an example of an individual with this unexpected relation. The hassle items that were endorsed by the woman at time 5 were examined. Although many items were endorsed as being *somewhat* of a hassle, items that were reported to be *a great deal* of a hassle were clearly in the financial realm. Although financial hassles disappear at time 6, overall health remains the same (does not change for the better). Points on the graph are relative to other points, and therefore, health that is not improving can appear to be

worsening because the distance between points has increased, rather than remaining the same. This can lead to a misleading interpretation.

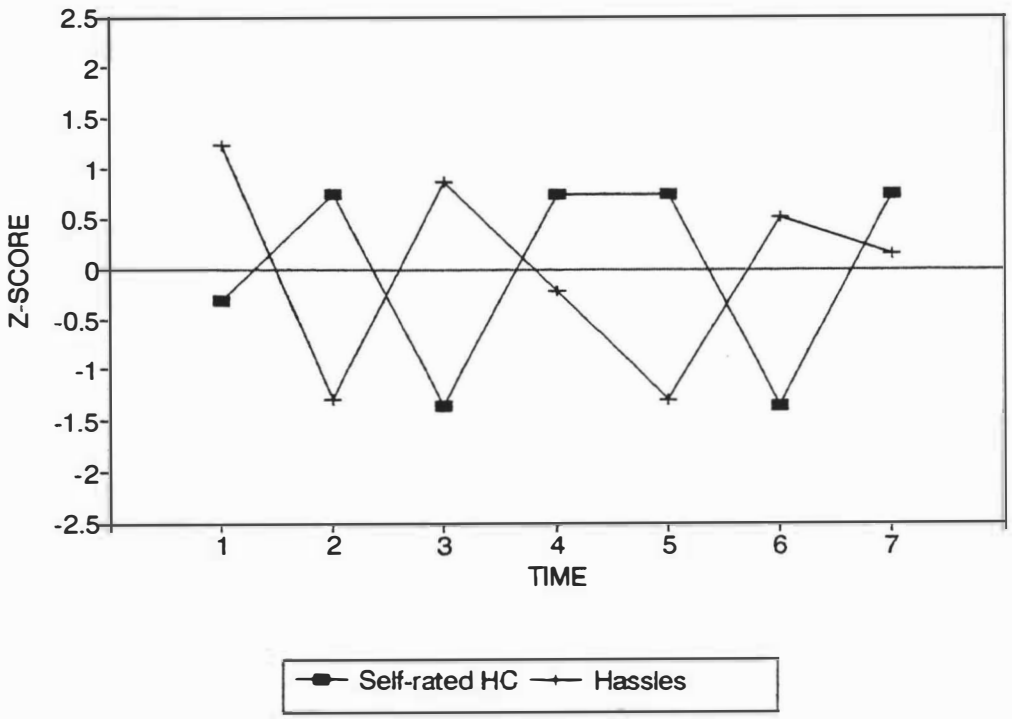


Figure 16. Intraindividual changes in self-rated health change and hassles over seven months (case 1).

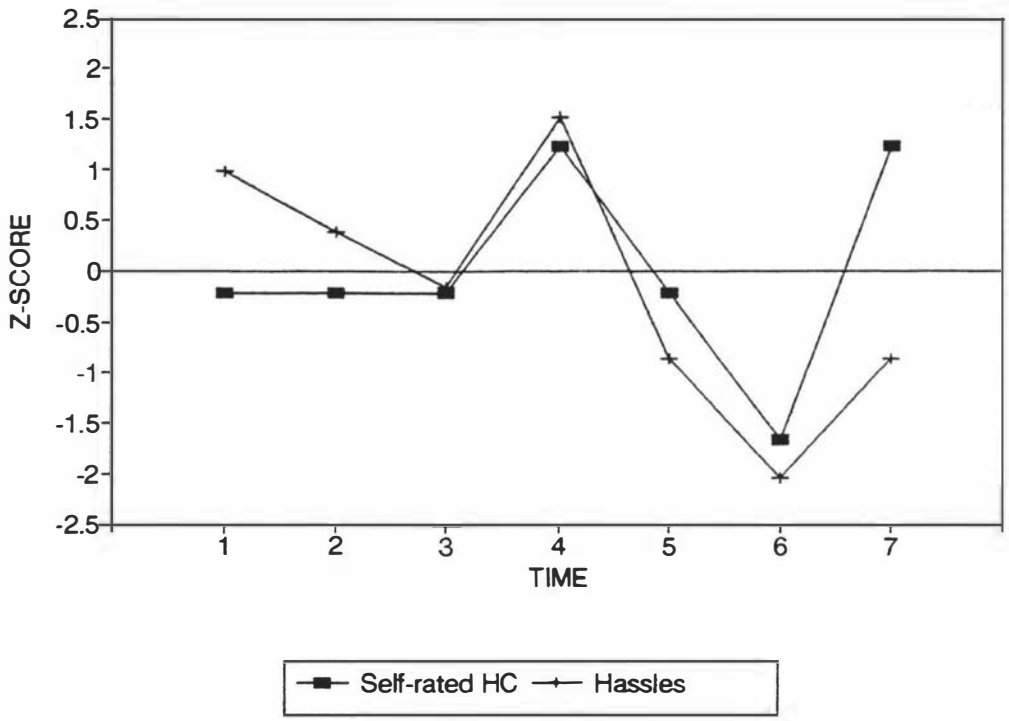


Figure 17. Intraindividual changes in self-rated health change and hassles over seven months (case 5).

SUMMARY

In summary, this section explored some relations, at the individual case level, that were found to be significant in the within-subject analyses. However, many of the significant within-subject relations, which were based on summary effects, did not demonstrate a definite pattern when examined at a case level, and therefore, were not included.

Of the relations that were considered, a few findings were found to be similar at both aggregate within-subject and individual case levels, and these will be discussed further in chapter 9. In these instances, greater credibility can be placed on the associations, which are validated at both levels. Some of the individual patterns that emerged did not replicate those established from summary effects. Although it was expected that averaged responses would differ from individual responses, the discrepancy in findings has interesting implications. It is clear that if relations are considered at the summary level exclusively, valuable information about the individual can be overlooked. For

example, although people on average may not appear to experience hopelessness, extensive disability, or high levels of stressors, the case level findings indicate that particular individuals are exceptional in their responses and circumstances. Furthermore, interpreting data at the individual case level may suggest some useful interventions that will improve the quality of life for people with MS.

CHAPTER 8

AN ILLUSTRATIVE CASE STUDY

This chapter provides an in depth account of an individual in order to offer a further perspective on how psychosocial factors may relate to short-term physical health changes in a person with MS. It contributes an interpretation that is primarily qualitative in nature, capturing the experience of one woman before, during and directly after a major MS exacerbation. It was not anticipated that a major exacerbation, which happened infrequently, would occur during the relatively short duration of the present study. However, it provided a rare opportunity to glimpse, and gain a better understanding of, this devastating process.

The chapter begins with a brief history about the woman, and then discusses her personal circumstances during the time she was involved in the study. In particular, the woman's experiences over the critical period when the relapse occurred, together with some relevant data trends extracted from her questionnaires, are described.

Mary's exacerbation occurred shortly after the data collection phase of the study had concluded. However, the specialist physician contacted the researcher, after obtaining permission from Mary, to inform her of what had transpired. Mary volunteered to continue in the study and provide information for a case study. The first set of data was collected in the usual way at the rehabilitation unit three weeks prior to Mary's relapse. The second set, as well as additional contextual information, was collected in the hospital a few days later, during the time Mary was receiving treatment. (The physician based his assessments on Mary's condition prior to the commencement of treatment.) Therefore, two complete sets of data (psychosocial and physical measures) were available for comparison.

PERSONAL AND MEDICAL HISTORY

Mary is a very attractive 37 year old married woman with two children, aged 10 and 12. Her personal circumstances and medical history are fairly typical of someone with multiple sclerosis. Born and raised in New Zealand, she had an uneventful childhood, was well educated and married at a relatively young age. Her health was good until 1976 when she started experiencing mild symptoms of MS. As is very common, a firm diagnosis of MS was not reached until several years later. Mary has been diagnosed for 10 years, and her MS has demonstrated a relapsing-remitting pattern, although she feels she has been "slipping for about four years". Mary's MS is considered moderate, and although she has some mild disabilities, she does not perceive herself as handicapped. She has weakness in one leg causing a slight limp, and walks at times with the assistance of a walking stick. Until recently, Mary has coped well with her MS, and has led a very active and full life. She has experienced a good relationship with her husband, has been raising her two children, looking after her home, and working part time.

This year, however, her MS has been more active, and Mary has found that things have started to get on top of her. A number of events transpired in the months leading up to her latest, and worst exacerbation. Firstly, her husband changed jobs, and although it was a positive situation, it placed some added strain on the family. Next, she and her family purchased and shifted into another house. Mary found the organizing and packing for the move extremely exhausting. The new house required a lot of cleaning, and Mary was determined to do it herself. At the same time, Mary found the demands of her job, which required doing some physical tasks, were wearing her down. During this period, she was aware of increased fatigue, and needed more time to get dressed in the morning and recover in the evening.

Also during this period, Mary went on holiday with her immediate and extended family to the South Island. She was apprehensive before the trip, wondering if she could manage the hectic pace and also somewhat concerned about the way her relatives (who had not seen her in a while) would react to her. Her fears were confirmed during the

trip. Mary reported "seeing pity in people's eyes" and feeling like everyone noticed her physical condition. She felt isolated from her family and offended by their attitude towards her.

Although, as mentioned previously, Mary generally has a good relationship with her husband, she believes the intimate aspects of their relationship have deteriorated over the past year. She believes, that with her progressing MS, she has lost her attractiveness as a woman. Mary views herself as walking in a clumsy way, and generally not being desirable to her husband. She feels her sexual function has been impaired because of her increased fatigue. Although, Mary would like to engage in more affectionate, cuddling behaviour with her husband, she perceives him as backing off. Mary interprets this as rejection, which further reinforces her beliefs about her appearance.

In addition to these circumstances, other even more emotionally taxing events occurred in the month prior to her exacerbation. Her father, who had been ill with terminal cancer became suddenly worse. His cancer was in the final painful stages, and Mary found it difficult to watch him suffer. In addition, two of Mary's uncles, both brothers of her father, died in the month prior to her deterioration.

Mary reported that her relapse started with extreme fatigue. Her right leg, which was weak before, suddenly would not support her. Her left leg, which was previously unaffected became very weak. Mary lost her sense of balance while standing, and her balance when sitting became impaired. Her bladder became dysfunctional, and she had problems with both frequency of urination and retention of urine. She reported some cognitive difficulties. Even making simple decisions about what to eat became difficult. At this point she rang her specialist physician and was admitted into hospital. Mary underwent a treatment of six courses of high grade steroids to try and suppress her immune system, in an effort to slow down or stop the deterioration. Fortunately, the treatment (and enforced rest) did produce some remission of the symptoms, however, it certainly did not restore Mary to her prior level of functioning.

PATTERNS FROM THE DATA

The data, collected prior to and following Mary's relapse, will be interpreted in the light of contextual information, while emphasising the key (changing rather then stable) factors in the theoretical model.

Physical health changes

First, consideration will be given to Mary's physical health changes, as evaluated by her physician. Impairment was assessed by the Kurtze Disability Status Scales (DDS) and Functional Systems (FS). Mary's level of impairment increased from 6 to 7 on the DDS. Although, this may not appear to be a large increase, 7 represents the point at which a person is restricted to a wheelchair, when he/she formerly relied only on walking aids. Mary's level of neurologic dysfunction as assessed by FS, demonstrates an even greater change. Pyramidal function deteriorated from 3 to 4, brainstem deteriorated from 0 to 2, sensory deteriorated from 4 to 5, and bowel and bladder deteriorated from 0 to 3. These scores indicate that the exacerbation caused deterioration to occur in a number of areas, and was not restricted to any specific function.

Mary's ability to perform every day tasks, as measured by the Functional Independence Measure (FIM) also declined. Her greatest increase in disability was evident in the locomotion domain, since she could no longer walk or use stairs. She also showed decline, although to a lesser extent, in mobility, sphincter control, and self-care. There were no changes in her ability to communicate or in the social cognition area.

In terms of overall health change, the physician rated Mary's health as *very much worse than last month*, the most extreme rating possible. Three weeks earlier he had rated her overall health as *about the same as last month*.

Next, Mary's evaluation of her own health changes will be discussed. Following her exacerbation, Mary rated the frequency and intensity of her MS symptoms to be only

marginally worse (frequency, 37 prior, 39 after; intensity, 53 prior, 59 after.) This is an interesting contrast to the very dramatic changes assessed by the physician. Examining the symptoms that Mary rated as frequent and intense might assist in an interpretation of this discrepancy. Prior to the relapse, Mary rated a number of symptoms as frequent and intense: balance problems, spasticity, weakness, fatigue, pain, bowel problems, bladder problems, and numbness. Following the exacerbation, all of these symptoms remained frequent and intense, most to an even greater degree, with the exception of bowel problems, which were no longer of concern. For many items, the outer limit of the frequency scale *constantly a problem* was reached prior to the exacerbation. Symptoms that were not of concern before the relapse (e.g. visual disturbances, speech problems, pressure sores) did not become problematic afterwards. Therefore, it appears as if certain types of symptoms were already of major concern, and although, these worsened marginally after the exacerbation, new types of symptoms did not develop.

Mary's ability to perform everyday tasks, as (self) assessed using the Activities of Daily Living Scale (ADL), indicated increased disability in three areas: bladder, mobility, and stairs. Her ratings were generally consistent with the ratings the physician made on the FIM.

Mary, as the physician had done, rated her overall health change as *very much worse than last month*. In the evaluation prior to the exacerbation, Mary rated her health as *worse than last month*, and the physician, in contrast, had discerned that Mary's health had not changed during that month. This suggests that Mary could feel her health declining before the relapse actually occurred, and the contextual information discussed earlier also supports this possibility.

Changes in stressors

It is obvious when considering Mary's circumstances that several very stressful events transpired prior to her relapse. Examining the responses in Mary's questionnaire there appears to be a build up of major stressors. Seven weeks before her exacerbation Mary

reported one stressful life event (visit to the South Island) that influenced her life *quite a bit*, and just after her exacerbation (keeping in mind this assesses the month prior), she reported three stressful life events (death of two uncles, father in final stages of terminal cancer, and major relapse in MS) that each influenced her life *a great deal*. It can be argued that Mary's perception may have been affected by her relapse and that she was providing reasons to explain her exacerbation. However, taking into account the types of events she reported, this is unlikely. It is also notable that her relapse, although a physical change, also became a major stressor in its own right, adding to the weight of the life events score.

It is of interest to see what happened to Mary's chronic daily hassles over the same period. Seven weeks before her relapse, Mary had a hassles score of 49, and the score rose marginally to 53 following the exacerbation. However, in isolation this pattern is misleading because it does not reflect the bigger picture. The month before Mary obtained the score of 49, her hassles score was only 19. This suggests that hassles began accumulating well before the relapse occurred. Without another measure of hassles, in a months time, it is impossible to determine whether the relapse resulted in further hassles. It appears, however, that in this case, minor stressors were an antecedent to the exacerbation. Examining the types of hassles Mary endorsed, before and after her relapse, is also of interest. Prior to her relapse Mary endorsed hassles primarily related to family pressures (children, parents, relatives, family obligations, etc.) time pressures (pets, cooking, housework, taking care of paperwork, being organised, social commitments, etc.), and her health (health, physical abilities). These types of hassles are consistent with Mary's verbal reports about her experiences while on holiday in the South Island, and with things generally getting on top of her. Following the exacerbation, the hassles Mary endorsed were similar, but with greater emphasis on health concerns and the hospital environment (your environment, recreation and entertainment) and less emphasis on home based concerns (cooking, housework, etc.) since she was residing in the hospital. The change in reported hassles was again consistent with Mary's situation at the time.

Psychological changes

Before her relapse, Mary felt *mostly satisfied* with her life as a whole. After her exacerbation, she viewed her life slightly less satisfactory, as *mixed about equally satisfied or dissatisfied.* Following her relapse Mary's positive affect underwent a substantial decline (score dropped from 30 to 15). It is therefore clear, that Mary experienced lessened positive well-being after her exacerbation.

On the other hand, Mary did not demonstrate an increase in hopelessness after her relapse. It is interesting that neither her levels of depression nor anxiety (which had been previously low) increased after the relapse. Further, her negative affect became marginally less (score dropped from 29 to 26), after the exacerbation. Hence, overall, Mary demonstrated no change in negative well-being during this period.

It is notable that positive well-being demonstrated a definite decline, while negative well-being remained stable. This pattern is not theoretically inconsistent, given that positive well-being and negative well-being can be regarded conceptually as two separate constructs, however, it is certainly interesting. One can speculate about why this pattern emerged. It may be that Mary is not inclined towards depression or anxiety, and therefore her reactions to stressors impacted only on her positive emotions. It could indicate that Mary has a particular style of coping that protects her from negative well-being outcomes. It is possible that her dispositional attributes function as moderators of the stressors. Alternatively, it might suggest that, for Mary, denial and defence mechanisms become activated during times of extreme stress.

CONCLUSION

This case study illustrated some of the physical and psychosocial changes that occurred prior to and following a major exacerbation in MS. It was particularly interesting, because Mary is a typical example, in terms of sex, age, race, medical background, and personal circumstances, of a person with MS. Her story depicted the unpredictable nature of the illness, and the devastating outcome of a single exacerbation. It also

clearly demonstrated the interrelations of physical health, stressors, and psychological factors, during an active phase of MS.

One can not assume that Mary's experience of her relapse would be similar for other people with MS. However in Mary's case, her physical health, stressors, and psychological well-being, behaved in a manner that is consistent with both theoretical and common sense expectations. After the exacerbation, Mary's level of disability increased. Her reports of major life events and hassles increased progressively prior to her exacerbation and remained high afterwards. Mary's positive well-being decreased substantially following her relapse, although, surprisingly, no increases in negative well-being occurred.

The case also portrayed how a person's perception of their health concurs with their physician's views. In most instances, Mary's perception of her changing health and disability status was consistent with her physician's evaluation. However, it seems likely that Mary sensed her health "slipping" before more substantial health changes were noticed by her physician.

Overall, this case study illustrated the ordeal of one individual, during a time of stress, physical trauma, and emotional turmoil. The descriptive approach used in this chapter emphasised personal experience and contextual background information. The insights gained from this case study highlight the need to go beyond questionnaire data to gain a fuller understanding of the MS experience.

CHAPTER 9

DISCUSSION AND CONCLUSION

This chapter considers the value of the proposed theoretical model in depicting aspects of the multiple sclerosis illness process. It begins by reviewing and interpreting the results arising from the four analytic approaches. In this context, the merits of using aggregate versus individual level strategies to interpret the data are discussed. It then discusses the strengths and weaknesses of the model, and considers the appropriateness of the general methodological approaches used. Finally, limitations of the study are addressed and suggestions are made for future research.

INTERPRETATION OF CROSS-SECTIONAL FINDINGS

The relations in the model were first examined at a single point in time. This is akin to taking a snapshot and examining the relations in suspended animation where the only variability is that between subjects. These results are comparable to those reported in most previous studies, because, like the majority of findings, they are based on cross-sectional between-subject data.

As in any cross-sectional study, causal relationships cannot be inferred from the regression analyses for several reasons. Firstly, data was collected at the same time for all factors in the model and therefore it is not possible to determine whether an effect is concurrent with, precedes or follows another effect. Secondly, two factors may appear to be correlated, but this might be due to the presence of a third factor which is not included in the model. Thirdly, although the proposed theoretical framework suggests a direction for effects, regression analyses do not unequivocally test, and therefore cannot confirm, the direction. However, theory sometimes provides a valid reason for assuming particular views about direction and other aspects of causality. Furthermore, when testing moderating effects the direction is specified and interaction terms are formed to reflect a particular conceptual assumption, thereby constraining

interpretations.

A picture emerges from the present analyses which focus on the MS experience at a single point in time. People's dispositional characteristics and their level of chronic stressors are both related to their psychological well-being. Disposition is also related to a person's satisfaction with their social support. In contrast, there is no association between people's physical health and their psychological state. Certain aspects of people's health status are, however, associated with the level of chronic stressors they experience.

Disposition is a stable characteristic and therefore it is posited to influence psychological well-being, which is a changing state, rather than the reverse causal process. Based on this supposition, the present findings suggest that people's dispositional characteristics influence their psychological well-being.

People who were more optimistic tended to be less hopeless. This suggests that people who have a positive expectancy about life, anticipating that things will go well, are less likely to experience hopelessness.

Persons with a weaker sense of personal control tended to experience less positive feelings and more negative feelings. These findings imply that individuals with a weaker sense of personal control are less likely to experience joyous or exciting emotional states and more apt to encounter emotional distress. This agrees with previous findings which have reported strong personal control in MS patients to be associated with positive emotional outcomes (Devins et al., 1993; Halligan & Reznikoff, 1985). Individuals with a weaker sense of control over their health were also inclined towards less positive feelings. In a prior study, people with an internal health locus of control orientation were reported to experience less hopelessness (Hickey & Greene, 1989).

Persons with stronger life meaning and higher optimism tended to report being more satisfied with their lives. These findings imply that having a sense of purpose and a

positive expectancy about the future has a favourable effect on a person's perception of his or her contentment with life.

Higher levels of chronic stressors were associated with a number of negative psychological well-being outcomes. People with more hassles tended to experience more anxiety, more depression and more negative feelings. It is plausible that having a high level of stressors makes a person more prone to experiencing emotional distress. It is also feasible that people who are emotionally distressed report more hassles because their emotional state influences their perception of situational factors. The present finding agrees with prior research (Perry, 1992) that found lower levels of hassles to be associated with better life satisfaction. Major life events, which were also expected to relate to psychological well-being, demonstrated no association. This is interesting because the majority of prior research focusing on the role of stress in MS have conceptualised stress in this way.

Only one finding supported the position that disposition moderates the relation between stressors and psychological outcomes. People with a stronger sense of personal control were more likely to experience negative affect when faced with hassles. The form of the interaction did not support the conceptual expectation that a stronger sense of personal control would provide a positive function by assisting a person to cope with stressors. One possible explanation is that people who feel in control of their lives are more susceptible to negative feelings when circumstances are beyond their control.

Surprisingly, the present findings did not provide evidence for the role of social support in influencing psychological well-being. Previous studies have reported strong social support, in people with MS, to relate to higher self-esteem, lower psychological distress (Maybury & Brewin, 1984) and less depression (McIvor, 1984), and the absence of support to be associated with depression and uncertainty (Wineman, 1990) and suicidal tendency (Long & Miller, 1991). However, these studies conceptualised and evaluated social support differently from the present study, which may explain, in part, the discrepancy in findings.

The relation between disposition and social support was supported only by a single finding. Persons with stronger life meaning tended to be more satisfied with their social support. It is feasible that people with a sense of life purpose are more likely to view their social relationships as meaningful. Further, they may attract others because of their positive outlook and hence develop more substantial personal relationships. The present finding agrees with a previous study, focused on adaptation in MS, which demonstrated a relationship between supportiveness and purpose in life (Wineman, 1990). However in that study, purpose in life was regarded as an adaptational outcome, whereas in the present study, meaning in life is treated as a dispositional characteristic.

Some aspects of people's physical health status were related to the level of chronic stressors they experienced. Persons who experienced more intense symptoms tended to report higher levels of chronic stressors. It is feasible that when people are under stress their symptoms become more intense (or at least feel more intense). Alternatively, when symptoms are intense, individuals may perceive their personal circumstances as more demanding, and report more hassles.

People who reported having less disability experienced higher levels of chronic stressors. Although this may seem a contradictory finding, one possible explanation is that people who are less disabled are more actively involved in life, and therefore have the opportunity to be challenged by more stressors. An examination of the types of stressors endorsed by participants did not, on a whole, suggest that people with less disability experience concerns in a wider range of areas, although this was true for a few individuals. This highlights the limitation of using aggregate findings to make interpretations about individuals.

The relationship between physical health status and psychological well-being in people with MS was not supported by the current findings. Most previous research has provided evidence for this association. For example, McLellan et al. (1989) found disability to be related to depression. Gattens and Brookings (1993) reported positive affect and negative affect to be correlated with self-rated physical health. Zeldow and Pavlou (1984) found well-being was associated with fewer physical limitations. Rabins

et al. (1986) reported depression and anxiety to be associated with neurological impairment. In contrast to these findings, Harper et al. (1986) failed to demonstrate an association between severity of MS and psychological well-being, and suggested that changes in disease status may be more important than disease status per se. The relation of changes in physical health to changes in psychological well-being will be discussed further in the next section.

The other unexpected finding was that, with the exception of a single finding, disposition and social support did not moderate the association between stressors and psychological well-being, or the relation between psychological well-being and health status. This suggests that those relationships occur in the same way for all people, despite the personal characteristics they may possess. However, in this study a restricted range of personal characteristics were measured, and it is possible that other factors may function as moderators. Further, the cross-sectional nature of the data and the difficulty in detecting interaction effects in a small sample may have limited the likelihood of finding moderating effects.

Overall, the findings suggest that persons with stronger life meaning, stronger optimism, a stronger sense of control over their life and health, and a lower level of hassles will experience better psychological health. These findings confirm conceptual expectations and agree with findings reported in previous research. Unexpectedly, social support was not associated with psychological well-being, although prior research has supported a relation. Surprisingly, physical health status did not relate to psychological well-being. This finding did not concur with most previous studies which have reported a relation between psychological and disease-related factors. Finally, people with a higher level of hassles tended to exhibit more intense symptoms and be less disabled.

The cross-sectional findings provided a useful starting point for viewing the relationships of the factors in the theoretical model. However, they are limited because they present a static view of construct associations, and are based on aggregate findings that suggest how people respond on average, but may not be representative of any given individual. Further, they explain differences between people rather than changes that occur within

the individual.

INTERPRETATION OF WITHIN-SUBJECT AGGREGATE FINDINGS

This approach utilised a change model to examine within-subject aggregate changes for 12 patients over a seven month period. As might be expected, a different pattern of findings emerged when regarding the relationships from a perspective of change.

For many of the same reasons as for the between-subject analyses, causal relationships cannot be inferred from the within-subject analyses. Although time was included in the regressions, all data was combined for analysis, and specific time points were not considered. Rather, changes in one factor relative to changes in another factor were examined. It was not possible to determine the sequence or the direction of the effects using regression procedures. An apparent correlation between two factors might be due to a third factor not included in the model. As in the between-subject regressions, a particular direction for effects is presumed in tests of moderating relationships, thereby driving the interpretations.

Unlike the between-subject findings, disposition and social support did not directly influence changes in psychological well-being. In contrast, disposition and social support, influenced the way changes in stressors related to changes in well-being.

MS patients with a weaker sense of personal control were more likely than those with stronger personal control to experience increased hopelessness when faced with stressors, either major life events or hassles. However, people who had a stronger sense of control *over their health* were more likely to experience increased hopelessness than those with a weaker sense of control over their health, when confronted with a major life event. The discrepancy between the role of personal control in general and control over one's health specifically, suggests that although it is beneficial for people with MS to maintain a sense of control over their life (aspects that are actually controllable), attempting to maintain a sense of control over a chronic illness, characterised by uncertainty, may be detrimental. The position that maintaining a belief in personal

control over a chronic illness, in light of evidence to the contrary, poses a threat to adaptation, has been advocated by others (Burish et al., 1984). In a prior study, Affleck et al. (1987) found that patients with severe rheumatoid arthritis, who had a strong sense of control over the course of their illness, demonstrated greater mood disturbance and less positive adjustment.

Disposition and social support functioned to moderate the relation between changes in stressors and changes in life satisfaction. However, the form of the interaction did not support conceptual expectations. People with stronger life meaning or stronger optimism were more prone to worsening life satisfaction under stress than people with weaker life meaning or weaker optimism. One possible explanation for the optimism finding is that highly optimistic people, by the very nature of their positive expectancies about the future, are more vulnerable in the face of difficult situations. Tennen and Affleck (1987) argued that there are potential pitfalls to being highly optimistic, one of which is being more vulnerable when things go wrong.

An explanation about why people with strong life meaning are more vulnerable to stress, in terms of their life satisfaction, is not as straightforward. Although life meaning also involves expectancies about life and the future, people with stronger life meaning would not necessarily expect that things will always go well, and in fact, this characteristic should assist people in making sense out of difficult situations. It is possible that individuals with strong life meaning are more self-aware and have a less superficial view of life, and therefore report changes in life satisfaction more readily than those with low life meaning.

Another unexpected finding suggested that people with larger social support networks tended to become less satisfied with life when confronted with stressors, than did people with smaller networks. It is conceivable that people involved in many interpersonal relationships put a high value on socializing, and may therefore find stressors frustrating because they disrupt their social functioning. Alternatively, people with smaller networks may be more inner dependent compared with those who are involved with larger social networks. It is possible that this helps them to be more resilient in the face

of stressful situations. This latter explanation is supported by comments made by a participant who reported that he had no one to turn to for meeting certain needs, and yet was extremely satisfied with this arrangement. The man told the researcher that he didn't require other people because he was very able to deal with his own emotional needs. It was clear that he felt extremely good about not relying on other people.

Unlike the cross-sectional findings, which demonstrated no links between psychological well-being and physical health status, the longitudinal findings supported a relation between these factors. However, only a single finding supported a direct association, and the other findings suggested that disposition and social support moderate the way changes in well-being relate to changes in health status.

The direct association involved positive affect and disability. It suggested that as people's positive feelings increase, their ability improves, or alternatively, as their ability improves, they have more positive feelings. The model posits a reciprocal relation between psychological and physical health, and therefore, both interpretations are appropriate. The first explanation implies that positive feelings have a bearing on how well individuals are able to accomplish tasks. This is possible because when a person feels better emotionally he or she may be willing to try harder or take more risks. The second interpretation is equally feasible because individuals who are functioning better are more likely to experience positive emotions.

Health locus of control influenced the way changes in positive affect impacted on self-rated health, however the interpretation of the interaction did not agree with the conceptual expectation. Increased positive affect was associated with improvement in self-rated health for people with a weaker sense of control over their health, rather than for those with a stronger sense of control. As stated earlier, it is possible that having a stronger sense of control over one's health is not beneficial for people with MS, who suffer from a deteriorating illness that they realistically cannot control.

Meaning in life, optimism and locus of control each moderated the impact of emotional states on impairment status. Anxiety was related to worsening impairment for people

with weaker life meaning. It is feasible that anxiety may contribute to deterioration in health in the absence of an orientation to life that enables people to make sense out of their personal circumstances and perceive them as meaningful. Although neither anxiety nor life meaning appear to singularly have a bearing on impairment changes in MS, a negative emotional state in the presence of a pessimistic expectancy about life appears to have a detrimental effect on impairment.

Positive affect was associated with improved impairment status in individuals who had a stronger sense of personal control. The same argument can be advanced here, from the opposite perspective. Neither positive feelings nor having a sense of personal control appears to influence changes in a person's degree of impairment. However, positive emotions in the presence of a confident expectancy, may have a beneficial effect on impairment. It is important to consider that improvement in MS is more unusual than deterioration in MS because of the progressive nature of the illness, and hence the recovery in impairment, at least for some people, will be temporary.

Hopelessness was linked to improvement in impairment status for highly optimistic people. It seems unlikely that hopelessness would be related to improvement in impairment status, but it is possible that highly optimistic people may override negative feelings with positive thinking. In another unexpected finding concerning optimism, positive affect was related to worsening impairment in highly optimistic people. This is contrary to the position that positive emotions function in conjunction with a positive expectancy to improve impairment. One possible explanation is that highly optimistic people are more in denial, and because the denial is not grounded in reality it is unlikely to have a beneficial effect on impairment. However, this is speculative given the converse view that denial in illness and disability can be healthy (Druss & Douglas, 1988; Taylor, 1983).

As the findings involving social support were anomalous, it is difficult to draw any definite conclusions about the role of social support as a moderator of emotional states. In the first finding, depression was related to improvement in self-rated health, in people whose social support network is small. It seems logical that depression would relate to

a deterioration in health rating, rather than an improvement. The second finding indicated that hopelessness was associated with improvement in impairment status, in people who experience dissatisfaction with their social support. Again, it would be expected that hopelessness would be associated with worsening impairment, instead of a betterment.

The findings provided some evidence for an association between changes in physical health and changes in stressors. Worsening health, as represented by changes in self-rated health, and increasing intensity of MS symptoms were both related to an increasing level of hassles. This agrees with the between-subject findings, where an association between symptom intensity and hassles was demonstrated. It is likely that when health changes for the worse or symptoms become more intense, everyday demands become more noticeable, and adjustments in many areas of life need to be made. This can certainly produce more chronic stressors, or, at the very least, colour the way individuals perceive their situation. People might be inclined to report more stressors when circumstances feel overwhelming, as during times of poor health. Alternatively, it is feasible that a person who is experiencing more hassles would tend to perceive his or her symptoms as more intense. Perhaps hassles consume personal energy that individuals would, under other circumstances, use for dealing with their symptoms.

Overall, the findings support some aspects of the theoretical model but fail to support others. The general picture that arises out of the findings suggests that, at least to some extent, dispositional characteristics and social support have a role in determining how changes in stressors impact on changes in psychological well-being, and suggests how changes in emotional states impact on changes in physical health. However, given the anomalous findings involving social support, its appropriateness as a moderator is questionable. The findings also suggest that certain aspects of people's changing physical state are linked to changes in the level of chronic stressors they experience.

Examining the changing relationships provided a different, and more revealing, view of what people experience during the course of MS than did the between-subject

findings. However, relationships were examined at an aggregate level, suggesting average response patterns, but were unable to capture what any particular individual was experiencing. People with MS vary considerably in their symptoms, level of impairment and disability, emotional responses, and individual characteristics. Thus it was important to look intraindividually to gain a more complete understanding of how individuals experience their illness.

INTERPRETATION OF INTRAINDIVIDUAL FINDINGS

For each of twelve people over seven months, the variables comprising the various constructs in the theoretical model were examined for level and variability. Physical health status was also examined for trend. The present study did not include a comparison group, and hence, in the main, levels were not compared to people without MS, but were considered relative to other participants in the longitudinal study. The overall impression gained was that most people did not experience a high level of stress, although a minority reported many hassles and/or recent life events. It was surprising, given the intrusive nature of MS, that more people did not report higher levels of stressors. It was anticipated that most people with MS would experience some degree of psychological distress, and because of the deteriorating and incurable nature of the disease, some people would feel hopeless at times; however, these assumptions were not supported. Most people did not appear to be depressed, anxious, or have excessive negative feelings, although a few were clearly distressed at times. No one felt consistently hopeless. Positive feelings and strong satisfaction with life were reported by most, but not all, participants.

As expected, people varied in their degree of impairment, frequency and intensity of symptoms, but surprisingly only one person showed substantial disability. As impairment levels differed, this was not a problem with sampling. On a whole, people were incredibly good at compensating for their impairment, and continued to perform daily tasks, despite their physical limitations.

People's level of stressors and psychological well-being tended to vary somewhat from

month to month, with the exception of hopelessness, which remained at low levels, with a single exception. Most people with MS experience occasional exacerbations of their disease, followed by stable periods when their disease is not active. Therefore as expected, over the seven month period, most individuals did not vary from month to month in terms of their impairment or disability. However, for some people a gradual worsening of impairment was evident. For most people, symptoms tended to change somewhat in terms of frequency and intensity, from month to month. This suggests that even during stable periods of the disease, symptoms can fluctuate, at least to some extent.

Overall, variables comprising the various constructs in the model related to one another, over time, in line with conceptual expectations. One of the more surprising findings was that as a person became more depressed, anxious, or experienced more negative feelings, he or she did not necessarily feel more hopeless. It was expected that, because of the incurable and often disabling nature of MS, some people would experience periods of hopelessness. Furthermore, previous research has suggested that MS patients are prone to feelings of hopelessness (Hickey & Greene, 1989; Mei-Tal et al., 1970). Although depression, anxiety and negative affect changed in unison for most people, changes in hopelessness were out of step with the other negative well-being variables. This may be partly a result of the way the variables are conceptualised and measured. Though depression, anxiety and negative affect all required an assessment of a person's emotional state, hopelessness was more of a cognitive evaluation. Participants were not directly asked if they were feeling hopeless, but rather they were asked to make judgements about how they anticipated their future. This is similar to the distinction in focus between evaluating positive affect and life satisfaction which, not surprisingly, are not related over time for most people.

Another unexpected finding, was that the two disability variables, FIM and ADL, did not change in unison, over time. One possible explanation is that one is a self-report measure and the other a physician assessed measure, and therefore, the ability to perform particular tasks were evaluated from two different perspectives. Evidence for this position is provided from an incident that occurred during the study. In chapter 6

a situation was described concerning a man who spent time in the hospital following extensive plastic surgery. During that period his level of disability, in terms of the tasks he was able to perform, was evaluated by both a physician and himself. The view of the physician was that the man could accomplish considerably less than the patient believed he could achieve, based on his self-report measure. When the researcher inquired about this discrepancy, the man commented that he was assessing what he thought he could do if he were not in the hospital. In contrast, the physician recorded what the man was actually doing at the time. Thus, it is clear from this example that two different sets of criteria were being used to make judgements about the level of disability.

Interestingly, unlike the assessment of disability, health change was viewed very much the same way by individuals and the physician. This suggests that people tend to agree with their physician in terms of general health changes. This may be a consequence of reporting their views about their health to the physician, which then get incorporated into the physician's evaluation. Alternatively, the MS patient and physician may consider similar aspects of health when making the assessment. Whatever the reason for agreement, it is probably a good indication that the evaluation, based on two separate sources, is valid.

For the most part, when within-subject interaction effects were examined at an individual level, no clear patterns emerged. This illustrates that although aggregate findings provide an average response pattern, they may not actually represent the experience of any given person. This is extremely important to consider because researchers often make the assumption that aggregate findings, particularly if they are in line with conceptual expectations, are capturing what is happening for specific individuals. As Valsiner (1986) proposed, it may be more appropriate to start with the individual and develop those findings into theoretical models, than to start with aggregate findings and try to generalise them to the individual.

There were, however, a few instances when aggregate findings were also detectable at an individual level. In three instances, findings were similar at both an aggregate and

individual level. Firstly, for people with stronger life meaning, as hassles increased, life satisfaction decreased. Although this seems an unlikely finding based on conceptual expectations, in the previous section a possible explanation was offered concerning why people with stronger life meaning may be more likely to report changes in their life satisfaction than those with weaker life meaning. Secondly, for people with weaker life meaning, as anxiety increased, impairment worsened. This finding implies that life meaning serves a protective function, or at least that the absence of strong life meaning leaves a person open to the potentially damaging effects of anxiety on physical health. Thirdly, people's level of hassles is related to their self-rated health change. As people's health changes for the better, they experience less hassles, and as their health changes for the worse, they experience more hassles. This finding suggests that worsening health has an affect on many areas of life, creating additional demands on the person; or alternatively that when a person feels worse, they do not cope as well and consequently report more hassles.

Examining findings at the individual level had several advantages. Firstly, it allowed an exploration of variable patterns for each person. Variable levels and variability were inspected and variable associations within each construct were examined as they changed over time. Secondly, in utilizing contextual information to assist with the interpretation of the quantitative findings, it provided a clearer understanding about the circumstances that encompass changes in stressors, psychological states and physical health status. Thirdly, it presented an opportunity to establish whether summary findings could be replicated at the individual level.

DISCUSSION OF THE CASE STUDY

The case study of Mary provided a good illustration of how several of the factors in the theoretical model function over time. It was clear that Mary's exacerbation of her illness was preceded by both a build up of chronic stressors and several major life events. Further, Mary was able to sense her health becoming unstable prior to the actual relapse. In particular, she was aware of becoming easily fatigued and taking longer to accomplish her normal activities. Mary was aware that her illness placed a

strain on her social relationship, in particular with her husband and her extended family. Her relapse and resulting hospitalisation created additional, but different stressors, and in itself was another major life event. Following the exacerbation, Mary reported less positive affect and decreased satisfaction with life, indicating that the relapse had caused some degree of emotional distress. However surprisingly, she did not experience increased anxiety, depression, hopelessness or negative affect.

The case study, though unusual because it described an acute exacerbation rather than the more subtle health changes that occur in MS, provided support for the theoretical model. It also confirmed the validity of the health status measures, as useful instruments in MS research. Changes in Mary's health corresponded to increased impairment, increased disability, and negative changes in self-assessed and physician assessed health. The contextual information provided a rich background from which to discuss the quantitative findings.

CONCLUSIONS REGARDING THE THEORETICAL MODEL

Each of the four analytic approaches examined the theoretical model from a different perspective. Considering all of the findings together, some support is provided for the model, but on balance not strong support. Most of the factors in the model appear to be conceptually relevant to the MS experience, and this is highlighted by the case study. However, the model fell short of capturing the relationship between psychosocial and physical changes over the short term course of multiple sclerosis.

As discussed earlier, psychological well-being is viewed as the pivotal factor in the model, because it posits that ultimately any changes in physical health result from an imbalance in a person's psychological equilibrium, usually when taxed by (perceived) stressful circumstances or events. This is certainly not an original theory and has been incorporated in several other chronic illness or illness models (e.g. Ben-Sira, 1984; Cohen & Wills, 1985; Lazarus & Folkman, 1984). However, results of the present study do not give strong support to this framework.

Although this study proposed that stressors had an impact on somatic factors through emotional and cognitive channels, it is also conceivable that stressors directly impact on physical health. This position assumes that stressors trigger a physiological reaction that create disturbances in somatic functioning. However, the correlations between the stressor and health status variables were, in the main weak, and do not provide evidence for this view.

It is likely that the association between psychological factors and physiological disturbance in MS is exceedingly complex. The present findings suggest that at times when health is relatively stable, as was the case for most people in the study, there is overall, only a weak relation between stressors, psychological factors, and disease activity. It is possible that this association becomes more pronounced during times of illness exacerbation. The case study, although an exceptional example, suggests that these factors are related during times of relapse. Findings from previous studies also provide evidence that MS patients in remission show substantially less emotional disturbance than those in exacerbation (Dalos et al., 1983; Warren et al., 1991).

It is feasible that biological factors, which are unknown and hence unmeasurable, interact with psychological factors to impact on somatic health. As relatively little is known about the causes of MS, it is difficult to speculate about what biological factor or factors may contribute to the progress of the illness.

Although it may be possible that biological influences combine with psychological influences in determining the progress of the disease, it seems logical that changes in health status, particularly increases in deterioration and disability, would evoke psychological reactions. The current study is unable to address this issue fully because most people were relatively stable throughout the study. However, the cross-sectional data certainly indicates that, at any given time, psychological and somatic factors are not related. The present findings suggest that, contrary to conceptual expectations, residual emotional effects from exacerbations are not evident during stable periods of the illness. This implies that the adjustment following a relapse takes place quickly. It has been suggested that psychologists have overestimated the emotional and social

impact of MS (Eklund & MacDonald, 1991). However, this view is based on interpreting data from a battery of self-report measures, which, for reasons that will be discussed later, may not provide an accurate picture of how people are functioning.

The nature of adaptation in multiple sclerosis needs to be better understood. The very essence of MS, as a chronic and deteriorating illness, means that, for many people, changes will be ongoing. Therefore adaptation occurs following the initial diagnosis, and then may recur at intervals, after each exacerbation. Adaptation implies that a positive psychosocial process has occurred for the individual. This is sometimes referred to as accommodation, and implies that the person is taking an active role in coping with his or her illness, although with some modification of goals (Radley & Green, 1987). It is important to distinguish accommodation from resignation, which suggests that a person has been overwhelmed by his or her illness and has essentially given in to it. From an observational perspective, the difference in these two responses may be difficult to discern because in both cases the person has stopped struggling with his or her illness and acceptance has, ostensibly, occurred.

The position that disposition and social support moderate the stressor-psychological relation and the psychological-physical health relation was not strongly supported, although the findings provide more evidence for the former. The view that individual difference factors function as moderators has been incorporated into many previous illness models (e.g. Cohen & Wills, 1985; Antonovsky, 1979; Kobasa, 1979), with an emphasis on their role in buffering the effects of stressors on health outcomes. Some of the present findings suggest that certain dispositional characteristics exert an effect on impairment in the presence of a particular emotional state. A positive emotion in conjunction with a positive expectancy impacts in a beneficial way, whereas, a negative emotion in conjunction with a negative expectancy impacts in a detrimental way. However, there were also findings that did not fit this pattern, most notably those involving optimism, and hence a definitive statement cannot be made.

Aside from these core issues, some other aspects of the model deserve comment. For some people, the degree of optimism they convey appears unrealistic given their

personal circumstances. In a recent qualitative study focused on veterans with MS, Barton et al. (1994) also observed that individuals faced life with an "overpowering optimism" (p. 92). It has been suggested (Schwarzer, 1994; Tennen & Affleck, 1987) that people who are highly optimistic may be particularly vulnerable when things go wrong. People may fail to engage in appropriate preventative behaviour or comply with medical regiments when they believe they are invulnerable (Tennen & Affleck, 1987). Early theories about people with MS, based on clinical observations, posited an MS personality, which sometimes included morbid optimism as a feature (Surridge, 1969). Although later theories dismissed the premise that MS patients have personality characteristics in common, observations made during the current study suggest that, to some extent, people with MS tend to avoid facing the reality of their illness. The overwhelming uncertainly of the disease, inability to determine a prognosis and the incurable nature of MS, would tax the resources of even the most well adjusted individuals. Although some MS patients appear to deny reality at times, it is more likely that this reflects an adaptational style, and is a response to the illness, rather than a premorbid personality type. It has been proposed that, because of the high degree of perceived uncertainty in MS, individuals may create positive illusions to protect themselves from the threat of the illness (Wineman, 1990).

The inclusion of health locus of control in the present model appears unfounded. The present findings provide minimal evidence for its role in directly affecting psychological well-being or as a buffer of stressors. In a chronic illness, where uncertainty is a characteristic of the disease, it may not be beneficial to believe one can control the course of his or her illness, particularly when the disease is severe (Afflect et al., 1987). A differing view is that a sense of mastery over the unpredictable course of MS is an important aspect of the illness experience (Robinson, 1990). However, the benefit of striving for a goal that is unattainable is questionable. On the other hand, having a sense of control about life in general does seem to have beneficial effects, and warrants inclusion in future studies. This position is supported by a recent investigation (Devins et al., 1993) that found, for people with MS, personal control was a key factor in determining psychosocial well-being.

Social support was another factor in the model which gained little support from the findings. When considered at a single point in time, social support did not relate to any other factor in the model, except meaning in life. When viewed from a change perspective, social support appeared to function as a moderator of stressors and emotional states, and yet, in several instances sensible interpretations of the interactions could not be made. This may be partly attributable to using aggregate statistics to draw conclusions about individual cases. This position is given some credibility because one of the anomalous aggregate findings became sensible when reinterpreted at the individual level. However, this did not happen in other instances and therefore theoretical issues should also be considered. Although a strong case can be made for the important role of social relationships in the MS experience (Barton et al., 1994; Robinson, 1988), it is possible that only certain aspects of a person's social network warrant consideration. For example, being left by a spouse might have much greater consequences for psychological well-being, than inclusion in a general social network. The author's observation was that, indeed, people tended to be more concerned with their primary relationships (particularly immediate family) than they were with their social group at large. Individuals' "tendency to pull away from friendships and focus on their family as the major source of support " was also noted in the qualitative findings of Barton et al. (1994, p. 90). Moreover, as mentioned earlier, a person may prefer to have a small network, and may take pride in not needing other people to provide emotional support.

It is difficult to make a general comment about which factors in the model are most useful in explaining the MS experience because each analytic approach provided a different perspective of the illness process. When the model is viewed statically, the most consistent relations occurred between stressors and psychological well-being, and between disposition and psychological well-being. Whereas, from a dynamic perspective, disposition featured as a moderator of the relation between changes in stressors and changes in psychological well-being, and between changes in psychological well-being and changes in physical health status. From both viewpoints, certain aspects of physical health status were associated with stressors. A few of the aggregate findings were replicated at the individual level. The intraindividual findings indicated that the

variable associations within the factors comprising the model were generally in line with conceptual expectations. Finally, the case study implied that both stressors and psychological well-being precede and follow a relapse in the disease, supporting those aspects of the model.

Although the present model, and the constructs comprising it, demonstrated only limited success in illustrating the MS experience, it can still be argued that this type of model, from a process perspective, is appropriate. Firstly, the current model is, in the main, concerned with change. It is clear that the course of multiple sclerosis involves factors that change over time. Although several models have focused on adaptation to MS, which implies change, they have been tested using cross-sectional data (e.g. Perry, 1992; Pollock et al., 1990; Wineman, 1990). An exception is illustrated by the Brooks and Matson (1982) study which considered changes in self concept over a seven year period. Secondly, the present model posited a reciprocal relation between psychological and physical health factors. The case study illustrated the necessity of considering some factors (e.g. stressors, psychological well-being) as both antecedents and reactions to disease activity. Most previous models propose a one way association between illness related factors and adaptational outcomes (e.g. Devins et al., 1993; Pollock et al., 1990; Wineman, 1990). Perry's (1990) model, which posits several reciprocal associations between psychosocial factors, is a notable exception, although it does not include physical health indicators. Thirdly, the current model is characterised by moderating relationships. It makes the assumption that relationships (of factors in the model) will be different for people depending on their personal characteristics or situation. Previous models have generally posited direct relationships (e.g. Devins et al., 1993; Perry, 1992; Pollock et al., 1990; Wineman, 1990), not taking into account individual differences. Research in this field require models that can examine both static and changing relationships, consider individual differences, separate psychosocial processes from disease processes, and discriminate between the effects of the illness process on psychosocial factors, and conversely, the effects of psychosocial factors on the illness process.

METHODOLOGICAL CONSIDERATIONS

In the present study conventional procedures were followed to optimise the likelihood that the results would reflect the experience of the participants involved. For example, measures were selected that demonstrated good reliability and validity. Further, some measures were modified to capture more pure constructs and in some cases, to avoid confounding with other constructs in the model. Beyond this, certain measures were revised to be more appropriate for use with MS patients. A range of health indicators were included and most importantly, some medically derived health status measures were administered by a physician. This avoided the limitation imposed by using exclusively subjective reports (usually symptom checklists) that may overlap with psychological factors (Watson & Pennebaker, 1989).

However, even reliance on a strong conceptual foundation and appropriate methodology did not yield results that provided strong support for the theoretical model. At this point it can be concluded that the model has somehow fallen short of representing the MS experience or, alternatively, that the MS experience may not be easy to capture using conventional measures and a structured interview format. Probably both are true to some extent. The adequacy of the model was discussed in the previous section, and some methodological concerns will be discussed here.

Spending a substantial period of time with people suffering from MS brought the author many insights into the illness process that could not be gleaned from second hand sources. Interactions with the participants provided, in the final analysis, some of the most valuable understanding about what people with MS experience during the course of their illness.

It is the author's position, after completing this research, that people with MS have a tendency to be stoic and use denial as a defence mechanism. To some extent this may serve a positive function by preventing them from becoming overwhelmed by the uncertainty of their disease. However, it also indicates an inability to deal with the

reality of their illness. The role of denial in adaptation to illness, as described in the literature, is controversial, being viewed as both a constructive, health promoting response to illness (Druss & Douglas, 1988; Taylor, 1983) and as an indication that the person has not come to terms with his or her illness (Radley & Green, 1987). In a recent study, Perry (1992) found that people with MS who used less avoidance coping, were more satisfied with their present health.

In the author's view, establishing rapport and then proceeding with a structured interview will not ensure that accurate information is collected. Some participants' answers will be filtered by denial or a need to appear stoic, regardless of their actual circumstances. There is a tendency for people to minimize their problems when responding to formal questions. The interview situation is artificial and the person is aware that his or her responses are being recorded. He or she may not want to be seen as a victim and may therefore offer responses that will create a particular impression. In addition there are time constraints and restrictions about what the person is allowed to discuss.

On the other hand, if enough time is spent with individuals, in an informal manner, they appear to overcome their initial tendency to censor information, and will speak more openly. This was clearly illustrated by the sensitive information that was conveyed to the author following the structured interview while chatting informally over a cup of tea. On the whole, a deeper level of information was relayed and negative feelings about living with MS invariably emerged more strongly at this point. Even people with mild MS expressed concern about the disease intruding into their lives.

For example, a woman initially presented with a happy facial expression and assurances that her illness did not disrupt her life. After the interview she told the author about the terrible pain she experienced at night from muscle spasms in her legs. She was being treated for this condition by her physician who had prescribed a particular medication. Initially the medication worked, but gradually she needed to take more of the medication to get relief. She was currently only one pill away from taking the maximum allowed dose. She showed the pills to the author and then disclosed that she was forcing herself

not to take the last pill, because if she did she would have no hope left.

Another example concerns a man who was still engaged in full time employment. The interview took place at his work and he was joking and pleasant throughout. He basically said that everything was fine in his life and his questionnaire reflected this attitude. As the author was about to leave, he asked if he could discuss something personal. He confessed that his sexual function was impaired and that this worried him a great deal. Although he was more tired that usual, he didn't think his impotence was a direct result of his disease. His wife had been greatly stressed by his diagnosis. She had always had mild psoriasis, but in recent months the condition had flared-up, becoming severe. Her psoriasis produced a body odour that prevented him from having sexual feeling towards her. Naturally, his withdrawal created further stress which contributed to her worsening condition. He had not raised the subject with either his physician or his wife.

People with severe MS communicated even more problematic life situations, which again, did not come across during the structured interview. For example one woman, totally confined to a wheelchair, but seemingly very content, was intent on demonstrating how independent she was, despite her disabilities. After the interview, she told the author that her husband left her because he could not deal with her MS, and that her sister who was currently living with her, also intended to move out. She had severe pain in her back which prevented her from getting more than three hours sleep each night. Although she found the nights very difficult, she refused pain medication (against her physician's advise) because she believed it would accelerate the disease process.

Another example concerns a man who had recently lost the use of his voice (needing to use a computer to speak), his ability to swallow, and was being feed by tubes that extended down his throat directly into his stomach. At the interview, despite his disabilities, he maintained a positive attitude. Afterwards he commented that he was greatly disturbed because he could no longer eat the things he enjoyed, and had to be attached to the tubes for many hours because of the time it took to get the liquid food

into his stomach.

Accounts of how disruptive MS was, in terms of its impact on people's lives, were not exceptional. Several people reported that partners or spouses left them after they were diagnosed with MS. Several people admitted to being in constant pain. Many people, unable to work, were living on a sickness benefit, and were under tremendous financial strain. In fact very few people did not express some degree of negative impact the disease had on their life. However, the structured interviews certainly did not reflect this level of distress. This does not necessarily indicate that appropriate measures or questions were missing from the questionnaire. Rather, it may be an indication of the way people with MS are likely to respond to a structured interview.

LIMITATIONS OF THE STUDY AND SUGGESTIONS FOR FUTURE RESEARCH

One limitation of the present study was the use, in the main, of a structured interview format for collecting information, and the methodological concerns arising from this discussed in the previous section.

Another drawback was the small sample size in the cross-sectional phase of the study. Although this was unavoidable on practical grounds, it had ramifications for the way the data could be analyzed. Due to the small sample size, a statistical approach that was capable of examining the model as a whole, such as structural equation modelling, was not advisable. Examining relationships within the model was an acceptable alternative, but relied on piecemeal correlational and regression statistics, and causality could not be established. However, even if a structural equation modelling approach had been used, causality could not necessarily have been determined.

Another limitation arising out of the within-subject analysis strategies involved the assumption made about the timing of effects. It was presumed that changes in one factor occurred concurrently with changes in another factor. This may not be a correct assumption. Patterns in data were examined as they covaried, rather than using a time

lag technique to determine, for example, if stressors at time one had an effect on psychological well-being at time two. However, it was not possible to use a systematic time lag technique in the present study because there were no conceptual grounds for determining the appropriate time interval between a particular cause and effect.

To optimise the opportunity to capture changes during the course of MS, the time frame of this study, ideally, should have been longer. However, for practical reasons, including the commitment of time allowed by the physician, this was not possible. The nature of MS for most people is to have relatively stable periods of health, punctuated by disease activity. It follows that a longer time frame would have included periods of disease activity for more participants, thereby providing more variability in the data.

Evaluating dispositional optimism as a single dimensional construct presented a minor drawback in this study. Recent evidence suggests that the Life Orientation Inventory measures a bi-dimensional construct, comprised of an optimism and pessimism component (Schwarzer, 1994). Although this position is arguable, there may have been advantages in assessing optimism differently.

In terms of the physician assessments, it would have been preferable to have blind ratings, thereby avoiding any possible bias arising from making multiple assessments on the same person. However, for practical reasons it was impossible to involve more than one physician in this research project. Moreover, the advantages of one observer ensured that the same criteria was used for every evaluation. In addition, this arrangement was more comfortable for the participants because they were able to establish a relationship with the physician.

Future research should, as in the current study, include a medical evaluation of physical changes due to MS. Although the Kurtzke measures (Kurtzke, 1965) used in this study, are commonly used in MS research, the development of medically derived measures that assess more subtle changes in MS would be a welcome addition. These measures need to be as non-invasive as possible, for ethical reasons and to insure co-operation between the physician and the participants.

Investigating the psychosocial correlates of the course of multiple sclerosis is difficult for several reasons. The greatest obstacle, in this author's view, is the difficulty in obtaining an accurate representation of the MS experience from people who, on the whole, tend to minimise the effects of their illness. Although the present findings suggest that people with MS are basically not suffering from emotional distress, clinical impressions provide a contradictory view. People with MS tend, as mentioned previously, to use denial, minimise their difficulties and compensate extremely well when physical deterioration occurs. Although these defence mechanisms appear to allow individuals to cope with their illness (Taylor, 1983), they are factors that may potentially confound research. The role of defence mechanisms in the coping process is a subject that merits further study. Several studies have already investigated the effects of coping strategies on adjustment to MS (e.g. Brooks & Matson, 1982; Hickey & Greene, 1989; Perry, 1992), however, more information is needed on this topic, particularly in regard to the unconscious processes underlying the choice of coping strategies.

Future research on psychosocial influences on the course of multiple sclerosis may be improved by using methodological approaches that combine qualitative and quantitative research techniques. The most profound insights about the MS illness process may be gained when conceptual relationships are considered against abundant contextual information about individuals. It has been suggested that the impact of a disease or a treatment on a patient can best be understood by collecting information on the experiential aspects of chronic illness, which can be accomplished through qualitative research with a case orientation (Gerhardt, 1990). Although this type of approach has not been used extensively in MS research, techniques such as diary methods (Lawson, Robinson & Bakes, 1985) and personal narratives (Robinson, 1990) have shown promise.

A final point worth noting is that the experience of relating to people with MS, some of whom are clearly suffering, has implications for researchers in this field. It requires an investigator with strong compassion coupled with an ability to remain objective to what the participant is communicating. This demands a delicate balance of personal

caring and professional detachment. Excessive emotional involvement results in stress for the researcher, whereas too much detachment prevents a trusting relationship from developing. One cannot fully understand the MS illness without seeing participants as individuals, with their hopes and dreams, and their anguish and disappointments.

REFERENCES

Abramson, L. Y., Metalsky, G. I., & Alloy, L. B. (1993). Hopelessness. In C. G. Costello (Ed.) *Symptoms of depression* (pp. 181-205). New York: Wiley.

Affleck, G., Tennen, H., Pfeiffer, C., & Fifield, J. (1987). Appraisals of control and predictability in adapting to a chronic illness. *Journal of Personality and Social Psychology*, *53*, 273-279.

Andrews, F. M., & Withey, S.B. (1976). *Social indicators of well-being: America's perception of life quality*. New York: Plenum.

Antonovsky, A. (1979). *Health, stress and coping*. San Francisco: Jossey-Bass Inc.

Antonovsky, A., Leibowitz, U., Medalie, J. M., Smith, H. A., Halpern, L., & Alter, M. (1968). Reappraisal of possible etiologic factors in multiple sclerosis. *American Journal of Public Health*, *58*, 836-848.

Barrera, M., Jr. (1986). Distinctions between social support concepts, measures, and models. *American Journal of Community Psychology*, *14*, 413-445.

Barton, J. A., Magilvy, J. K., & Quinn, A. A. (1994). Maintaining the fighting spirit: Veterans living with multiple sclerosis. *Rehabilitation Nursing Research*, *3*, 86-96.

Beck, A. T., Weissman, A., Lester, D., & Trexler, L. (1974). The measurement of pessimism: The Hopelessness Scale. *Journal of Consulting and Clinical Psychology*, *42*, 861-865.

Ben-Sira, Z. (1984). Chronic illness, stress and coping. *Social Science and Medicine*, *18*, 725-736.

Bolger, N., DeLongis, A., Kessler, R. C., & Schilling, A. (1989). Effects of daily stress on negative mood. *Journal of Personality and Social Psychology*, *57*, 808-818.

Broadhead, E. B., Kaplan, B. H., James, S. A., Wagner, E. H., Schoenbach, V. J., Grimson, R., Heyden, S., Tibblin, G., & Gehlbach, S.H. (1983). The epidemiologic evidence for a relationship between social support and health. *American Journal of Epidemiology*, *5*, 521-537.

Brooks, N. A., & Matson, R. R. (1982). Social-psychological adjustment to multiple sclerosis: A longitudinal study. *Social Science and Medicine*, *16*, 2129-2135.

Burish, T., Carey, M., Wallston, K., Stein, M., Jamison, R., & Lyles, J. (1984). Health locus of control and chronic illness: An external orientation may be advantageous. *Journal of Social and Clinical Psychology*, *2*, 326-332.

Burks, J. S. (1992). A review of the current medical aspects of multiple sclerosis. *Journal of Neurologic Rehabilitation*, *6*, 129-139.

Burks, N., & Martin, B. (1985). Everyday problems and life change events: Ongoing versus acute sources of stress. *Journal of Human Stress*, *11*, 27-34.

Buttle, F. (1980). *The Elley-Irving Socio-Economic Indices: Practical problems in their use* (Research Report No. 26). Palmerston North: Massey University, Market Research Centre.

Calder, V., Owen, S., Watson, C., Feldmann, M., & Davison, A. (1989). MS: A localized immune disease of the central nervous system. *Immunology Today*, *10*, 99-103.

Carver, C. S. (1989). How should multifaceted personality constructs be tested? Issues illustrated by self-monitoring, attributional style, and hardiness. *Journal of Personality and Social Psychology*, *56*, 577-585.

Chamberlain, K. (1988). On the structure of subjective well-being. *Social Indicators Research*, *42*, 581-604.

Chamberlain, K., & Zika, S. (1988). Measuring meaning in life: An examination of three scales. *Personality and Individual Differences*, *9*, 589-596.

Chamberlain, K., & Zika, S. (1990). The minor events approach to stress: Support for the use of daily hassles. *British Journal of Psychology*, *81*, 469-481.

Cohen, A. (1962). Personality aspects of multiple sclerosis: A review of the literature from 1950 through 1961. *Journal of Rehabilitation*, *28*, 18-20, & 50-51.

Cohen, S., & Wills, T. A. (1985). Stress, social support and the buffering hypothesis. *Psychological Bulletin*, *98*, 310-357.

Costa, P. T., & McCrae, R. R. (1987). Neuroticism, somatic complaints, and disease: Is the bark worse than the bite? *Journal of Personality*, *55*, 299-316.

Counte, M. A., Bieliauskas, L. A., & Pavlou, M. (1983). Stress and personal attitudes in chronic illness. *Archives of Physical Medicine and Rehabilitation*, *64*, 272-275.

Crumbaugh, J. C. (1968). Cross-validation of Purpose in Life Test based on Frankl's concepts. *Journal of Individual Psychology*, *24*, 74-81.

Crumbaugh, J. C., & Maholick, L. T. (1964). An experimental study in existentialism: The psychometric approach to Frankl's concept of noogenic neurosis. *Journal of Clinical Psychology*, *20*, 200-207.

Dalos, N. P., Rabins, P. V., Brooks, B. R., & O'Donnell, P. (1983). Disease activity and emotional state in multiple sclerosis. *Annals of Neurology*, *13*, 573-577.

Data Management Service of the Uniform Data System for Medical Rehabilitation. (1987). *Guide for the use of the uniform data set for medical rehabilitation*. New York: The Buffalo General Hospital.

DeLongis, A., Coyne, J. C., Dakof, G., Folkman, S., & Lazarus, R.S. (1982). Relationships of daily hassles, uplifts, and major life events to health status. *Health Psychology*, *1*, 119-136.

DeLongis, A., Folkman, S., & Lazarus, R. S. (1988). The impact of daily stress on health and mood: Psychological and social resources as mediators. *Journal of Personality and Social Psychology*, *54*, 486-495.

Devins, G. M., & Seland, T. P. (1987). Emotional impact of multiple sclerosis: Recent findings and suggestions for future research. *Psychological Bulletin*, *101*, 363-375.

Devins, G. M., Seland, T. P., Klein, G., Edworthy, S. M., & Saary, M. J. (1993). Stability and determinants of psychosocial well-being in multiple sclerosis. *Rehabilitation Psychology*, *38*, 11-26.

Diener, E. (1984). Subjective well-being. *Psychological Bulletin*, *95*, 542-575.

Disler, P. B., Gregory, R. J., Firth, S., & Disler, S. A. (1993). Epidemiology of multiple sclerosis in the Manawatu region of New Zealand. Paper presented at the XIIth Annual Scientific Meeting of the Australasian College of Rehabilitation Medicine.

Dohrenwend, B. S., Dohrenwend, B. P., Dodson, M., & Shrout, P. E. (1984). Symptoms, hassles, social supports, and life events: Problem of confounded measures. *Journal of Abnormal Psychology*, *93*, 222-230.

Dowall, J. R. (1989). *The effects of social support on occupational stress and mental health*. Unpublished master's thesis, Massey University, Palmerston North, New Zealand.

Dufton, B. D., & Perlman, D. (1986). The association between religiosity and the Purpose in Life Test: Does it reflect purpose or satisfaction? *Journal of Psychology and Theology*, *14*, 42-48.

Druss, R. G., & Douglas, C. J. (1988). Adaptive responses to illness and disability. *General Hospital Psychiatry*, *10*, 163-168.

Dyck, M. J. (1987). Assessing logotherapeutic constructs: Conceptual and psychometric status of the Purpose in Life and Seeking of Noetic Goals Tests. *Clinical Psychology Review*, *7*, 439-447.

Edwards, J. R., & Cooper, C. L. (1988). The impact of positive psychological states on physical health: A review and theoretical framework. *Social Science and Medicine*, *27*, 1447-1459.

Eklund, V. A., & MacDonald, M. L. (1991). Descriptions of persons with multiple sclerosis, with an emphasis on what is needed from psychologists. *Professional Psychology Research and Practice*, *22*, 277-284.

Folstein, M. F., & Folstein, S. E. (1975). "Mini-Mental State": A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, *12*, 189-198.

Foote, A. W., Piazza, D., Holcombe, J., Paul, P., & Daffin, P. (1990). Hope, self-esteem and social support in persons with multiple sclerosis. *Journal of Neuroscience Nursing*, *22*, 155-159.

Frankl, V. (1959). *Man's search for meaning*. London: Hodder & Stoughten.

Frankl, V. (1967). *Psychotherapy and existentialism*. New York: Simon & Schuster.

Franklin, G. M., Nelson, L. M., Heaton, R. K., Burks, J. S., & Thompson, D. S. (1988). Stress and its relationship to acute exacerbations in multiple sclerosis. *Journal of Neurologic Rehabilitation*, *2*, 7-11.

Friedman, H. S. (1990). Personality and disease: Overview, review, and preview. In H. S. Friedman (Ed.), *Personality and disease* (pp. 3-13). New York: John Wiley & Sons.

Garrity, T. F., Somes, G. W., & Marx, M. B. (1987). Factors influencing self-assessment of health. *Social Science and Medicine*, *12*, 77-81.

Gatten, C. W., & Brookings, J. B. (1993). Mood fluctuations in female multiple sclerosis patients. *Social Behavior and Personality*, *21*, 103-106.

Gerhardt, U. (1990). Qualitative research on chronic illness: The issue and the story. *Social Science and Medicine*, *11*, 1149-1159.

Granger, C. V., Dewis, L. S., Peters, N. C., Sherwood, C. C., & Barrett, J. E. (1979). Stroke Rehabilitation: Analysis of repeated Barthel Index measures. *Archives of Physical Medicine and Rehabilitation, 60*, 14-17.

Granger, C. V., Hamilton, B. B., Keith, R. A., Zielezny, M., & Sherwin, F. S. (1986). Advances in functional assessment for medical rehabilitation. *Topics in Geriatric Rehabilitation, 1*, 59-73.

Granger, C. V., Cotter, A. C., Hamilton, B. B., Fiedler, R. C., & Hens, M. M. (1990). Functional assessment scales: A study of persons with multiple sclerosis. *Archives of Physical Medicine and Rehabilitation, 71*, 870-875.

Grant, I. (1993). Psychosomatic-somatopsychic aspects of multiple sclerosis. In U. Halbreich M.D. (Ed.), *Multiple sclerosis: A neuropsychiatric disorder* (pp. 119-136). Washington, DC: American Psychiatric Press, Inc.

Grant, I., Brown, G. W., Harris, T., McDonald, W. I., Patterson, T., & Trimble, M. R. (1989). Severely threatening events and marked life difficulties preceding onset or exacerbation of multiple sclerosis. *Journal of Neurology, Neurosurgery, and Psychiatry, 52*, 8-13.

Grant, I., McDonald, W. I., Patterson, T., & Trimble, M. R. (1989). Multiple sclerosis. In G. W. Brown & T. O. Harris (Eds.), *Life events and illness* (pp. 295-311). London: Upwin Hyman.

Gresham, G. E., Phillips, T. F., & Labi, M. L. C. (1980). ADL status in stroke: Relative merits of three standard indexes. *Archives of Physical Medicine and Rehabilitation, 61*, 355-358.

Gulick, E. E. (1994). Social support among persons with multiple sclerosis. *Research in Nursing and Health, 17*, 195-206.

Gruen, R. J., Folkman, S., & Lazarus, R. S. (1988). Centrality and individual differences in the meaning of daily hassles. *Journal of Personality*, *56*, 743-762.

Halligan, F. R., & Reznikoff, M. (1985). Personality factors and change with multiple sclerosis. *Journal of Consulting and Clinical Psychology*, *53*, 547-548.

Harper, A. C., Harper, D. A., Chambers, L. W., Cino, P. M., & Singer, J. (1986). An epidemiological description of physical, social and psychological problems in multiple sclerosis. *Journal of Chronic Diseases*, *39*, 305-310.

Headey, B., Kelley, J., & Wearing, A. (1993). Dimensions of mental health: Life satisfaction, positive affect, anxiety and depression. *Social Indicators Research*, *29*, 63-82.

Hesketh, B. L. (1982). *Psychological aspects of unemployment: Attributes about the causes of success and failure in job seeking*. Unpublished doctoral dissertation. Massey University, Palmerston North, New Zealand.

Hickey, A., & Greene, S. M. (1989). Coping with multiple sclerosis. *Irish Journal of Psychological Medicine*, *6*, 118-124.

Holmes, T. H., & Masuda, M. (1974). Life change and illness susceptibility. In B. S. Dohrenwend & B. P. Dohrenwend (Eds.), *Stressful life events: Their nature and their effects* (pp. 45-72). New York: Wiley.

Holmes, T. H., & Rahe, R. H. (1967). The Social Readjustment Rating Scale. *Journal of Psychosomatic Research*, *11*, 213-218.

Jaccard, J., Turrisi, R., & Wan, C. (1990). *Interaction effects in multiple regression*. Newbury Park, Calif.: Sage Publications.

Jones, W. H. (1985). The psychology of loneliness: Some personality issues in the study of social support. In I. G. Sarason & B. R. Sarason (Eds.), *Social support: Theory, research and applications* (pp.225-241). Dordrecht: Martinus Nijhoff.

Kanner, A. D., Coyne, J. C., Schaefer, C., & Lazarus, R. S. (1981). Comparison of two modes of stress measurement: Daily hassles and uplifts versus major life events. *Journal of Behavioral Medicine*, *7*, 1-39.

Kobasa, S. (1979). Stressful life events, personality and health: An inquiry into hardiness. *Journal of Personality and Social Psychology*, *37*, 1-11.

Kurtzke, J. F. (1965). Further notes on disability evaluation in multiple sclerosis, with scale modifications. *Neurology*, *15*, 654-661.

Kurtzke, J. F. (1970). Neurologic impairment in multiple sclerosis and the Disability Status Scale. *Acta Neurologica Scandinavica*, *46*, 513-526.

Kurtzke, J. F. (1983). Rating neurologic impairment in multiple sclerosis: An expanded disability status scale (EDSS). *Neurology*, *33*, 1444-1453.

Kurtzke, J. F. (1984). Disability rating scales in multiple sclerosis. *Annals of the New York Academy of Sciences*, *436*, 347-360.

Kurtzke, J. F. (1988). Multiple sclerosis: What's in a name? *Neurology*, *38*, 309-316.

Lafferty, A. R. A., McKay, D. P. R., Matthews, A. J., Sipeli, F. P., & Trotman, P. J. (1988). *Multiple sclerosis: Medical and social needs evaluated.* Dunedin: University of Otago, Department of Preventive and Social Medicine.

Langworthy, O. R. (1948). Relation of personality problems to onset and progress of multiple sclerosis. *Archives of Neurology and Psychiatry*, *59*, 13-28.

LaRocca, N. G. (1984). Psychosocial factors in multiple sclerosis and the role of stress. *Annals of the New York Academy of Sciences*, *436*, 435-442.

Lau, R. R. (1988). Beliefs about control and health behavior. In D.S. Gochman (Ed.), *Health behavior: Emerging research perspectives* (pp. 43-63). New York: Plenum Press.

Lawson, A., Robinson, I., & Bakes, C. (1985). Problems in evaluating the consequences of disabling illness: The case of multiple sclerosis. *Psychological Medicine*, *15*, 555-579.

Lazarus, R. S., & DeLongis, A. (1983). Psychological stress and coping in aging. *American Psychologist*, *38*, 245-254.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.

Lechtenberg, R. (1988). *Multiple sclerosis fact book* (2nd ed.). Philadelphia: Davis.

Lezak, M. D. (1983). *Neuropsychological assessment* (2nd ed.). New York: Oxford University.

Long, D. D., & Miller, B. J. (1991). Suicidal tendency and multiple sclerosis. *Health and Social Work*, *16*, 104-109.

Maddox, G. L., & Douglass E. B. (1973). Self-assessment of health: A longitudinal study of elderly subjects. *Journal of Health and Social Behavior, 14*, 87-93,

Mahoney, F. I., & Barthel, D. W. (1965). Functional evaluation: The Barthel Index. *Maryland State Medical Journal*, *14*, 61-65.

Marshall, G. N., & Lang, E. L. (1990). Optimism, self-mastery, and symptoms of depression in women professionals. *Journal of Personality and Social Psychology*, *59*, 132-139.

Maybury, C. P., & Brewin, C. R. (1984). Social relationships, knowledge and adjustment to multiple sclerosis. *Journal of Neurology, Neurosurgery, and Psychiatry*, *47*, 372-376.

McIvor, G. P., Riklan, M., & Reznikoff, M. (1984). Depression in multiple sclerosis as a function of length and severity of illness, age, remissions, and perceived social support. *Journal of Clinical Psychology*, *40*, 1028-1033.

McLellan, D. I., Martin, J. R., Roberts, M. H. W., Spackman, A., McIntosh-Michaelis, S., & Nichols, S. (1989). *Multiple sclerosis in the Southampton District*. University of Southampton: Rehabilitation Research Unit and Department of Sociology and Social Policy.

Meier, A., & Edwards, H. (1974). Purpose in Life Test: Age and sex differences. *Journal of Clinical Psychology*, *30*, 384-386.

Mei-Tal, V., Meyerowitz, S., & Engel, G. L. (1970). The role of psychological process in a somatic disorder: Multiple sclerosis. *Psychosomatic Medicine*, *32*, 67-86.

Melamed, B. G., & Brenner, G. F. (1990). Social support and chronic medical stress: An interaction-based approach. *Journal of Social and Clinical Psychology*, *9*, 104-117.

Minden, S. L., Orav, J., & Reich, P. (1987). Depression in multiple sclerosis. *General Hospital Psychiatry*, *9*, 426-434.

Minden, S. L., & Schiffer, R. B. (1990). Affective disorders in multiple sclerosis: Review and recommendations for clinical research. *Archives of Neurology*, *47*, 98-104.

Minden, S. L., & Schiffer, R. B. (1993). Depression and affective disorders in multiple sclerosis. In U. H. (Ed.) *Multiple sclerosis: A neuropsychiatric disorder* (pp. 33-54). Washington, DC: American Psychiatric Press, Inc.

Monroe, S. M., & Simons A. D. (1991). Diathesis-stress theories in the context of life stress research: Implications for the depressive disorders. *Psychological Bulletin*, *110*, 406-425.

Newcomb, M. D. (1990). Social support and personal characteristics: A developmental and interactional perspective. *Journal of Social and Clinical Psychology, 9*, 54-68.

Nisipeanu, P., & Korczyn, A. D. (1993). Psychological stress as risk factor for exacerbation in multiple sclerosis. *Neurology*, *43*, 1311-1312.

Omodei, M. M., & Wearing, A. J. (1990). Need satisfaction and involvement in personal projects: Towards an integrative model of subjective well-being. *Journal of Personality and Social Psychology*, *59*, 762-769.

Palmore, E., & Luikart, C. (1972). Health and social factors related to life satisfaction. *Journal of Health and Social Behavior*, *13*, 68-79.

Perry, S. (1992). *Living with multiple sclerosis: Personal accounts of coping and adaptation*. Aldershot: Avebury.

Peyser, J. M., Edwards, K. R., & Poser, C. M. (1980). Psychological profiles in patients with multiple sclerosis. *Archives of Neurology*, *37*, 437-440.

Peyser, J. M., & Poser, C. M. (1986). Neuropsychological correlates of multiple sclerosis. In S. B. Filskov & T. J. Boll (Eds.), *Handbook of neuropsychology* (pp. 364-397). New York: Wiley & Sons.

Philippopoulos, G. S., Wittkower, E. D., & Cousineau, A. (1958). The etiologic significance of emotional factors in onset and exacerbations of multiple sclerosis. *Psychosomatic Medicine*, *20*, 458-474.

Pollock, S. E. (1986). Human responses to chronic illness: Physiologic and psychosocial adaptation. *Nursing Research*, *35*, 90-95.

Pollock, S. E., Christian, B. J., & Sands, D. (1990). Responses to chronic illness: Analysis of psychological and physiological adaptation. *Nursing Research*, *39*, 300-304.

Poser, C. M. (1980). Exacerbations, activity, and progression in multiple sclerosis. *Archives of Neurology*, *37*, 471-474.

Poser, C. M. (1981). Trauma, stress, and multiple sclerosis. *Bulletin. American Academy of Psychiatry and the Law*, *7*, 209-218.

Rabins, P. V., Brooks, B. R., O'Donnell, P., Pearlson, G. D., Moberg, P., Jubelt, B., Coyle, P., Dalos, N., & Folstein, M. F. (1986). Structural brain correlates of emotional disorder in multiple sclerosis. *Brain*, *109*, 585-597.

Rabkin, J. G., & Struening, E. L. (1976). Life events, stress, and illness. *Science*, *195*, 1013-1020.

Radley, A., & Green, R. (1987). Illness as adjustment: A methodology and conceptual framework. *Sociology of Health and Illness*, *9*, 179-207.

Reker, G. T. (1977). The Purpose-in-Life Test in an inmate population: An empirical investigation. *Journal of Clinical Psychology*, *33*, 688-693.

Reker, G. T., & Cousins, J.B. (1979). Factor structure, construct validity and reliability of the Seeking of Noetic Goals (SONG) and Purpose in Life (PIL) tests. *Journal of Clinical Psychology*, *35*, 85-91.

Reker, G. T., & Wong, P. T. P. (1985). Personal optimism, physical and mental health. In J. E. Birren & J. Livingston (Eds.), *Cognition, stress and aging* (pp. 134-173). Englewood Cliffs: Prentice-Hall.

Reker, G. T., & Wong P. T. P. (1988). Aging as an individual process: Towards a theory of personal meaning. In J. E. Birren & V. L. Bengtson (Eds.), *Emergent theories of aging* (pp. 214-246). New York: Springer.

Robinson, I. (1988). *Multiple sclerosis*. London: Routledge.

Robinson, I. (1990). Personal narratives, social careers and medical courses: Analysing life trajectories in autobiographies of people with multiple sclerosis. *Social Science and Medicine*, *30*, 1173-1186.

Robinson, J. P., & Shaver, P. R. (1973). *Measures of social psychological attitudes* (rev. ed.). Michigan: Survey Research Centre.

Rotter, J. B. (1966). Generalized expectancies for internal versus external control of reinforcement. *Psychological Monographs*, *80*, 1-28.

Rotter, J. B. (1990). Internal versus external control of reinforcement: A case history of a variable. *American Psychologist*, *45*, 489-493.

Sarason, I. G. (1988). Social support, personality, and health. In M. P. Janisse (Ed.), *Individual differences, stress, and health psychology* (pp. 109-128). New York: Springer-Verlag.

Sarason, I. G., Levine, H. M., Basham, R. B., & Sarason, B. R. (1983). Assessing social support: The social support questionnaire. *Journal of Personality and Social Psychology*, *44*, 127-139.

Sarason, I. G., Sarason, B. R., & Pierce, G. R. (1990). Social support: The search for theory. *Journal of Social and Clinical Psychology*, *9*, 133-147.

Schaefer, C., Coyne, J. C., & Lazarus, R. S. (1981). The health-related functions of social support. *Journal of Behavioral Medicine*, *4*, 381-406.

Schaubroeck, J., & Ganster, D. C. (1991). Associations among stress-related individual differences. In C. L. Cooper & R. Payne (Eds.), *Personality and stress: Individual differences in the stress process* (pp. 33-66). Chichester: John Wiley & Sons.

Scheier, M. F., & Carver, C. S. (1985). Optimism, coping, and health: Assessment and implications of generalized outcome expectancies. *Health Psychology*, *4*, 219-247.

Scheier, M. F., & Carver, C. S. (1987). Dispositional optimism and physical well-being: The influence of generalized outcome expectancies on health. *Journal of Personality*, *55*, 169-210.

Scheier, M. F., & Carver, C. S. (1992). Effects of optimism on psychological and physical well-being: Theoretical overview and empirical update. *Cognitive Therapy and Research*, *16*, 201-228.

Scheinberg, L. C., & Smith, C. R. (1987). Signs and symptoms of multiple sclerosis. In L. C. Scheinberg & N. J. Holland (Eds.), *Multiple sclerosis: A guide for patients and their families* (2nd ed.)(pp. 43-51). New York: Raven.

Schroeder, D. H., & Costa, P. T. (1984). Influence of life event stress on physical illness: Substantive effects or methodological flaws? *Journal of Personality and Social Psychology*, *46*, 853-863.

Schubert, D. S. P., & Foliart, R. H. (1993). Increased depression in multiple sclerosis: A meta-analysis. *Psychosomatics*, *34*, 124-130.

Schwarzer, R. (1994). Optimism, Vulnerability, and self-beliefs as health-related cognitions: A systematic overview. *Psychology and Health*, *9*, 161-180.

Schwarzer, R., & Leppin, A. (1989). Social support and health: A meta-analysis. *Psychology and Health*, *3*, 1-15.

Schwarzer, R., & Leppin, A. (1991). Social support and health: A theoretical and empirical overview. *Journal of Social and Personal Relationships*, *8*, 99-127.

Siegert, R. J., Patten, M. D., & Walkey, F. H. (1987). Development of a brief social support questionnaire. *New Zealand Journal of Psychology*, *16*, 79-83.

Skegg, D. C. G., Corwin, P. A., Craven, R. S., Malloch, J. A., & Pollock, M. (1987). Occurrence of multiple sclerosis in the north and south of New Zealand. *Journal of Neurology, Neurosurgery, and Psychiatry*, *50*, 134-139.

Smith, T. W., Pope, M. K., Rhodewalt, F., & Poulton, J. L. (1989). Optimism, Neuroticism, Coping, and symptom reports: An alternative interpretation of the Life Orientation Test. *Journal of Personality and Social Psychology*, *56*, 640-648.

Strickland, B. R. (1978). Internal-external expectancies and health-related behaviors. *Journal of Consulting and Clinical Psychology*, *6*, 1192-1211.

Surridge, D. (1969). An investigation into some psychiatric aspects of multiple sclerosis. *Journal of British Psychiatry*, *115*, 749-764.

Tabachnick, B. G., & Fidell L. S. (1989). *Using multivariate statistics* (2nd ed.). New York: Harper & Row.

Taylor, S. E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. *American Psychologist*, *38*, 1161-1173.

Tennen, H., & Affleck, G. (1987). The costs and benefits of optimistic explanations and dispositional optimism. *Journal of Personality*, *55*, 377-393.

Thoits, P. A. (1982). Conceptual, methodological, and theoretical problems in studying social support as a buffer against life stress. *Journal of Health and Social Behavior, 23*, 145-159.

Valsiner, J. (1986). Different perspectives on individual-based generalizations in psychology. In J. Valsiner (Ed.), *The individual subject and scientific psychology* (pp. 392-404). New York: Plenum Press.

VanderPlate, C. (1984). Psychological aspects of multiple sclerosis and its treatment: Towards a biopsychosocial perspective. *Health Psychology*, *3*, 253-272.

Viet, C. T., & Ware, J. E. (1983). The structure of psychological distress and well-being in general populations. *Journal of Consulting and Clinical Psychology, 51*, 730-742.

Wallston, B. S., Alagna, S. W., DeVellis, B. M., & DeVellis, R. F. (1983). Social support and physical health. *Health Psychology, 2*, 367-391.

Wallston, K. A. (1992). Hocus-pocus, the focus isn't strictly on locus: Rotter's social learning theory modified for health. *Cognitive Therapy and Research, 16*, 183-199.

Wallston, K. A., & Wallston, B. S. (1982). Who is responsible for your health? The construct of health locus of control. In G. S. Sanders & J. Suls (Eds.), *Social psychology of health and illness* (pp. 65-95). Hillsdale, NJ: Erlbaum.

Wallston, K. A., Wallston, B. S., & DeVellis, R. (1978). Development of the Multidimensional Health Locus of Control (MHLC) Scales. *Health Education Monographs, 6*, 160-170.

Waltz, M., & Badura, B. (1990). Social support and chronic illness: Conceptual and methodological problems. *International Journal of Health Sciences, 1*, 177-183.

Warren, S. (1990). The role of stress in multiple sclerosis. In S. M. Rao (Ed.), *Neurobehavioral aspects of multiple sclerosis* (pp. 197-209). New York: Oxford University Press.

Warren, S., Greenhill, S., & Warren, K.G. (1982). Emotional stress and the development of multiple sclerosis: Case-control evidence of a relationship. *Journal of Chronic Diseases, 35*, 821-831.

Warren, S., Warren, K. G., & Cockerill, R. (1991). Emotional stress and coping in multiple sclerosis (MS) exacerbations. *Journal of Psychosomatic Research, 35*, 37-47.

Watson, D. (1988). Intraindividual and interindividual analyses of positive and negative affect: Their relation to health complaints, perceived stress, and daily activities. *Journal of Personality and Social Psychology, 54*, 1020-1030.

Watson, D., & Clark, L. A. (1992). Affects separable and inseparable: On the hierarchical arrangement of the negative affects. *Journal of Personality and Social Psychology, 62*, 489-505.

Watson, D., Clark, L. A., & Tellegen, A. (1988). Development and validation of brief measures of positive and negative affect: The PANAS Scales. *Journal of Personality and Social Psychology, 54*, 1063-1070.

Watson, D., & Pennebaker, J. W. (1989). Health complaints, stress and distress: Exploring the central role of negative affectivity. *Psychological Review, 96*, 234-254.

Weinberger, M., Hiner, S. L., & Tierney, W. M. (1987). In support of hassles as a measure of stress in predicting health outcomes. *Journal of Behavioral Medicine, 10*, 19-31.

Whitlock, F. A., & Siskind, M. M. (1980). Depression as a major symptom of multiple sclerosis. *Journal of Neurology, Neurosurgery, and Psychiatry, 43*, 861-865.

Willoughby, E. (1990). Multiple sclerosis. *The Disease Index, 1*, 288-291.

Wilcox, B., & Vernberg, E. (1985). Conceptual and theoretical dilemmas facing social support research. In I. G. Sarason & B. R. Sarason (Eds.), *Social support: Theory, research and application* (pp. 3-20). The Hague: Martinus Nijhoff.

Wineman, N. M. (1990). Adaptation to multiple sclerosis: The role of social support, functional disability, and perceived uncertainty. *Nursing Research, 39*, 294-299.

Wong, P. T. P. (1989). Personal meaning and successful aging. *Canadian Psychology*, *30*, 516-525.

World Health Organization. (1980). *International classification of impairments, disabilities, and handicaps.* Geneva: World Health Organization.

Yalom, I. D. (1980). *Existential psychotherapy*. New York: Basic Books.

Young, A. C., Saunders, J., & Ponsford, J. R. (1976). Mental change as an early feature of multiple sclerosis. *Journal of Neurology, Neurosurgery, and Psychiatry*, *39*, 1008-1013.

Zeldow, P. B., & Pavlou, M. (1984). Physical disability, life stress, and psychosocial adjustment in multiple sclerosis. *The Journal of Nervous and Mental Disease*, *172*, 80-84.

Zeldow, P. B., & Pavlou, M. (1988). Physical and psychosocial functioning in multiple sclerosis: Descriptions, correlations, and a tentative typology. *British Journal of Medical Psychology*, *61*, 185-195.

Zika, S., & Chamberlain, K. (1988). [Internal consistency of James LOC scale for mothers and elderly samples]. Unpublished data.

Zika, S., & Chamberlain, K. (1987). Relation of hassles and personality to subjective well-being. *Journal of Personality and Social Psychology*, *53*, 155-162.

Zika, S., & Chamberlain, K. (1992). On the relation between meaning in life and psychological well-being. *British Journal of Psychology*, *83*, 133-145.

APPENDIX A: LETTERS TO PARTICIPANTS

Letter from researcher

Letter from MS Society

Letter inviting participants to continue involvement in the study

RESEARCH PROJECT ON WELL-BEING OF PEOPLE WITH MULTIPLE SCLEROSIS

Facsimile

MASSEY
UNIVERSITY

Palmerston North
New Zealand
Telephone (063) 69-099

We are involved in an extensive study to learn about the things that lead to changes in the well-being and health of people with MS. I am the principal investigator, and my associates are Dr. John Spicer and Mr. Kerry Chamberlain from Massey University, and Dr. Peter Disler from the Palmerston North Hospital. The study will look at how people with MS feel and what they think about life, and the effects these things have on their MS condition. It will also focus on the stresses that people with MS experience in daily life. The findings from this study should provide information which will help in the treatment of MS and thereby increase the well-being of those afflicted. We believe this type of research is extremely valuable.

If you would like to help us with this research you will be asked to take part in one interview. I will come to your home at a convenient time and assist you to complete a questionnaire. This should take about one to two hours of your time. A few people will be invited to continue involvement with the project on a longer term basis. However, agreeing to an interview does not commit you to taking part in anything more.

Everything you tell us or write in your questionnaire will be completely confidential. Nobody, apart from us will see your answers and your name will not appear on the forms. You can decline to answer any questions that you object to or drop out of the study at any point.

We would greatly appreciate your assistance with this project. No one can tell us more about these things than you yourself. We believe that you will find it an interesting and rewarding experience. At the end of the study, all participants will receive a summary of our findings.

If you are interested in taking part in this study and would like me to phone you, please complete the information at the bottom of this letter and mail it back in the envelope provided. You do not need to put a stamp on this. Completing the form below does not mean you have to participate, it only provides an opportunity for you to discuss this with me. You can take the time you need to consider this matter before making a decision. Thank you.

Yours Sincerely,

Sheryl Zika
Researcher

MS RESEARCH PROJECT

I would like the researcher to phone me and give me further information about the study.

NAME: _____

TELEPHONE NUMBER: _____

THE MANAWATU MULTIPLE SCLEROSIS SOCIETY
Incorporated

P.O. BOX 194.
PALMERSTON NORTH.

25 February 1991

Dear Friend,

Mrs. Sheryl Zika is a researcher from the Department of Psychology at Massey University. She is doing an important research project on the well-being of people with multiple sclerosis.

She is asking for help from people with MS, such as yourself. The questionnaire will be easy to complete and Sheryl will be there to assist you with it. Although we know that some of you have taken part in other studies recently, the purpose of this study is quite different. Sheryl assured me that she would not be doing this study unless she thought that she would be getting new information.

The Manawatu branch of the MS Society has given their support to this research because we believe the findings will be valuable to people with MS. As the project is being funded by Massey University, it will not be of any cost to the MS Society. In addition, the research ethic committee of both Massey University and the Palmerston North Hospital Board have reviewed the study and given their approval.

Remember that this is completely voluntary and the choice to take part is entirely yours. If you want to participate Sheryl will be very happy to meet with you at your home.

Further details about the study are given in the attached letter. If you would like additional information I will be pleased to discuss it with you (73904).

Kind Regards, Ethel Robinson.

Ethel Robinson

RESEARCH PROJECT ON WELL-BEING OF PEOPLE WITH MULTIPLE SCLEROSIS

Dear

Thank you for your participation in our research project. The information we will gain from the interviews will be extremely valuable in assisting our understanding of the social, psychological and physical factors involved in MS. We are currently analysing this information and will be sending you a summary of the research findings as promised. Meanwhile, we would like to go a step further and try to find out what happens to these factors over time. To accomplish this, it is necessary to follow up a small group of participants over a period of months.

Participants in this part of the study will be asked to:

1. Go to the Rehabilitation Unit of the Palmerston North Hospital once a month for nine consecutive months and meet with Dr. Peter Disler who will perform a brief clinical examination. This will be similar to the usual MS examination, and will not include any intrusive tests. As usual, Dr. Disler will provide information about the progress of the MS condition and treat (or make referrals for) any other medical problems that are present.

2. Complete a set of questionnaires, one a month for nine months. Most of these will be shorter than the questionnaire you have already answered. I will meet you at the Rehabilitation Unit when you are there for your examination, and either assist you to complete the questionnaire, or provide you with instructions and arrange a time to collect it from you. Your participation in the study will take around two to three hours of your time each month.

If you agree to take part in this research we will reimburse you for your travel expenses, and of course all of your medical visits to the Rehabilitation Unit will be of no cost to you. As in the previous study, everything you tell us or write in your questionnaire will be completely confidential. Dr. Disler will keep normal hospital records of your clinical examinations and **only** provide me with a summary sheet which contains information which is relevant to this study. The information you provide in your questionnaires will not be given to Dr. Disler. A code number, **not your name**, will appear on this sheet and on all of your questionnaires. You have the right to decline to answer any questions, and to drop out of the study at any time.

We recognise that your participation in this study will require a considerable amount of time and energy. However, we believe that it will be of benefit to you. It will provide you with regular contact with a physician who will monitor your MS. You will have the opportunity over this nine month period to talk about any issues which may be of concern to you. In addition, you will be making a major contribution towards assisting us to find information which can ultimately improve the quality of life for people with MS.

If you are interested in participating in this part of the study or would like more information, please complete the form on the attached page and mail it back in the envelope provided. You do **not** need to put a stamp on this. Thank you.

Yours Sincerely,

Sheryl Zika

MS RESEARCH PROJECT

I would like the researcher to phone me and give me further information about this part of the study. I understand that completing this form is **not** a commitment to participate in the study, and that I can take the time I need to think this over.

Name:_____

Telephone number:_____

APPENDIX B: PARTICIPANT CONSENT FORMS

Cross-sectional study (consent form A)

Longitudinal study (consent form B)

RESEARCH PROJECT ON WELL-BEING OF PEOPLE WITH MULTIPLE SCLEROSIS

CONSENT FORM (A)

What would I have to do?

You would be asked to meet with the researcher at your home and complete one questionnaire. This will include questions about your MS condition, how you feel and what you think about life, things that are stressful to you and your social relationships. This should take around one to two hours of your time.

What can I expect from the researchers?

All participants:

* have the right to refuse to answer any particular question, and withdraw from the study at any time.

* provide information on the understanding that it is confidential to the researchers. All questionnaires are identified only by code number, and are only seen by the researchers. It will not be possible to identify individuals in any published reports.

* will receive a summary of the research findings after the information has been analysed.

The details of the study have been adequately explained to me, and I do/do not wish to participate under the conditions set above.

signature of participant_____

signature of researcher_____

date_____

RESEARCH PROJECT ON WELL-BEING OF PEOPLE WITH MULTIPLE SCLEROSIS

CONSENT FORM (B)

What would I have to do?

Go to the Rehabilitation unit of the Palmerston North Hospital once a month for nine consecutive months and meet with Dr. Peter Disler who will perform a brief clinical examination. This will be similar to the usual MS examination, and will not include any intrusive tests. As usual, Dr. Disler will provide information about the MS condition and treat (or make referrals for) any other medical problems that are present.

Complete a set of questionnaires, one a month for nine months. These will contain questions that are similar to the ones asked in the first questionnaire, but most questionnaires will be shorter. The researcher will meet you at the Rehabilitation Unit when you are there for your examination, and either assist you to complete the questionnaire, or provide you with instructions and arrange a time to collect it from you. Your participation in the study will take around two to three hours of your time each month

What can I expect from the researchers?

All participants:

* have the right to refuse to answer any particular question, and withdraw from the study at any time.

* provide information on the understanding that it is confidential to the researchers. All questionnaires are identified only by code number, and are only seen by the researchers. It will not be possible to identify individuals in any published reports. Medical records will be seen only by Dr. Disler, who will provide the researchers with a summary sheet with information relevant to the study. These will also be identified by code number.

* will receive a summary of the research findings after the information has been analysed.

* will receive reimbursement for travel expenses to and from the Rehabilitation Unit.

The details of the study have been adequately explained to me, and I do/do not wish to participate under the conditions set above.

signature of participant_____

signature of researcher_____

date_____

APPENDIX C: QUESTIONNAIRES

Cross-sectional questionnaire

Cognitive screening measure

Longitudinal questionnaire (change measures)

Physical examination questionnaire

Longitudinal questionnaire (stable measures)

MULTIPLE SCLEROSIS QUESTIONNAIRE

In this interview, we want to find out what sort of experiences you have and how you feel about them. We will be asking you a number of questions and hope that you will answer them carefully and honestly. Keep in mind that there are no right or wrong answers.

Occasionally you may think that we have already covered a topic, and have asked the same kind of question with a difference in wording. You will be right. However, it is important for our purposes that we ask these questions.

Your participation in this study is very important to us. We hope you will find the experience interesting and enjoyable.

We will begin by asking some questions about yourself, your living arrangements, and your medical history. Remember that everything you tell us is confidential and will not be used to identify you. We need these details to help up interpret the information we are collecting.

CARD 1

ID

How old were you on your last birthday ☐☐ years

Are you male or female? ☐ male ☐ female

What is your current marital status? (circle the appropriate number)

married (includes de facto) 1

widowed 2

separated/divorced 3

single 4

With whom do you live? (circle more than one if appropriate)

alone 1

with your spouse 2

with your dependent child(ren) 3

with a friend or companion 4

with your grown child(ren) 5

with your parent(s) 6

other _____ 7
(please explain)

To which ethnic group do you consider yourself to belong?

European/Pakeha 1

Maori 2

Pacific Islander 3

Other _____ 4
(please specify)

Are you currently employed? ☐ yes ☐ no

What is your usual occupation? _____

At what age were you diagnosed as having Multiple Sclerosis? ☐☐ years

Apart from MS, do you have any other chronic health condition(s)? ☐ yes ☐ no

If so, what is the name of this condition(s)? _____

In the first set of questions we want to ask about the hassles you have experienced this last month. Hassles are irritants that can range from minor annoyances to fairly major pressures, problems, or difficulties. Hassles can occur few or many times.

Below is a list of some things that can be considered hassles in day-to-day life. During the course of the last month some of these things will have been a hassle for you. Please think how much of a hassle each of these things was for you **during the last month**. Indicate on the right-hand side of the page (under "HASSLES") how much of a hassle each statement was by circling the appropriate number.

HASSLES
0 = Not at all or not applicable
1 = Somewhat
2 = Quite a bit
3 = A great deal

Remember you must circle one answer for every item.

Your child(ren) _____ 0 1 2 3

Your parents or parents-in-law _____ 0 1 2 3

Other relative(s) _____ 0 1 2 3

Your spouse _____ 0 1 2 3

Time spent with family _____ 0 1 2 3

Health or well-being of a family member _____ 0 1 2 3

Intimacy _____ 0 1 2 3

Family related obligations _____ 0 1 2 3

HASSLES
0 = Not at all or not applicable
1 = Somewhat
2 = Quite a bit
3 = A great deal

Your friend(s) _____ 0 1 2 3

Fellow workers _____ 0 1 2 3

Clients, customers, patients etc _____ 0 1 2 3

Your supervisor or employer _____ 0 1 2 3

The nature of your work _____ 0 1 2 3

Your work load _____ 0 1 2 3

Your job security _____ 0 1 2 3

Meeting deadlines or goals on the job _____ 0 1 2 3

Enough money for necessities (e g food, clothing, housing, health care, taxes) _____ 0 1 2 3

Enough money for education _____ 0 1 2 3

Enough money for emergencies _____ 0 1 2 3

Enough money for extras (e g vacations, recreation, entertainment) _____ 0 1 2 3

Financial care for someone who doesn't live with you _____ 0 1 2 3

Investments _____ 0 1 2 3

Your smoking _____ 0 1 2 3

Your drinking _____ 0 1 2 3

Mood-altering drugs _____ 0 1 2 3

Your physical appearance _____ 0 1 2 3

Contraception _____ 0 1 2 3

Exercise(s) _____ 0 1 2 3

Your medical care _____ 0 1 2 3

Sex _____ 0 1 2 3

Your health _____ 0 1 2 3

HASSLES
0 = Not at all or not applicable
1 = Somewhat
2 = Quite a bit
3 = A great deal

Your physical abilities _____ 0 1 2 3

The weather _____ 0 1 2 3

News events _____ 0 1 2 3

Your environment (e g quality of air, noise level, trees and greenery _____ 0 1 2 3

Political or social issues _____ 0 1 2 3

Your neighbourhood (e g neighbours, the area you live in) _____ 0 1 2 3

Conserving (gas, electricity, water, petrol, etc) _____ 0 1 2 3

Pets _____ 0 1 2 3

Cooking _____ 0 1 2 3

Housework _____ 0 1 2 3

Home repairs _____ 0 1 2 3

Yardwork _____ 0 1 2 3

Car maintenance _____ 0 1 2 3

Taking care of paperwork (e g paying bills, filling out forms) _____ 0 1 2 3

Home entertainment (e g T V, music, reading) _____ 0 1 2 3

Amount of free time _____ 0 1 2 3

Recreation and entertainment outside the home (e g movies, sport, eating out, walking) _____ 0 1 2 3

Eating (at home) _____ 0 1 2 3

Church or community organisations _____ 0 1 2 3

Legal matters _____ 0 1 2 3

Being organised _____ 0 1 2 3

Social commitments _____ 0 1 2 3

Now that we have considered your everyday hassles, we would like you to list any **major** events that have happened to you in the past month. Next, please indicate (circle) to what extent each event has influenced your life. If nothing major has taken place in your life during the past month please leave this section blank.

Event	not at all	somewhat	quite a bit	a great deal
_____	0	1	2	3
_____	0	1	2	3
_____	0	1	2	3

The next section asks questions about the way in which you view your life. For each of the following statements, circle the number that would be most nearly true for you. Note that the numbers always extend from one extreme to another. "Neutral" implies no judgement either way. Try to use number 4 **as little** as possible.

In life I have:

1 2 3 4 5 6 7
(neutral)

no goals or aims at all — very clear goals and aims

My personal existence is:

1 2 3 4 5 6 7
(neutral)

utterly meaningless without purpose — very purposeful and meaningful

If I could choose, I would:

1 2 3 4 5 6 7
(neutral)

prefer never to have been born — like nine more lives just like this one

After retiring, I would:

7 6 5 4 3 2 1
(neutral)

do some of the exciting things I have always wanted to — loaf completely the rest of my life

CARD 2

In achieving life goals I have:

1 2 3 4 5 6 7
(neutral)

made no progress whatever — progressed to complete fulfilment

If I should die today, I would feel that my life has been:

7 6 5 4 3 2 1
(neutral)

very worthwhile — completely worthless

In thinking of my life, I:

1 2 3 4 5 6 7
(neutral)

often wonder why I exist — always see a reason for my being here

As I view the world in relation to my life, the world:

1 2 3 4 5 6 7
(neutral)

completely confuses me — fits meaningfully

I am a:

1 2 3 4 5 6 7
(neutral)

very irresponsible person — very responsible person

With regard to death, I am:

7 6 5 4 3 2 1
(neutral)

prepared and unafraid — unprepared and frightened

With regard to suicide, I have:

1 2 3 4 5 6 7
(neutral)

thought of it seriously as a way out — never given it a second thought

I regard my ability to find a meaning, purpose, or mission in life as:

7 6 5 4 3 2 1
(neutral)

very great — practically none

I have discovered:

1 2 3 4 5 6 7
(neutral)

no mission or purpose in life — clear-cut goals and a satisfying life purpose

Next, we want you to consider how satisfied you are with your life. Please circle the number that best describes this for you.

How you do feel about your life as a whole?

- Terrible 1
- Very dissatisfied 2
- Mostly dissatisfied 3
- Mixed about equally satisfied or dissatisfied 4
- Mostly satisfied 5
- Very satisfied 6
- Delighted 7

Here are a number of statements about how people experience life. Please indicate to what extent you agree or disagree with each statement by circling the appropriate number.

In uncertain times, I expect the best.

- Strongly agree 1
- Agree 2
- Neutral 3
- Disagree 4
- Strongly disagree 5

If something can go wrong for me it will.

- Strongly agree 1
- Agree 2
- Neutral 3
- Disagree 4
- Strongly disagree 5

I look on the bright side of things.

- Strongly agree 1
- Agree 2
- Neutral 3
- Disagree 4
- Strongly disagree 5

I'm optimistic about my future.

- Strongly agree 1
- Agree 2
- Neutral 3
- Disagree 4
- Strongly disagree 5

I do not expect things to go my way.

- Strongly agree 1
- Agree 2
- Neutral 3
- Disagree 4
- Strongly disagree 5

Things do not work out the way I want them to.

- Strongly agree 1
- Agree 2
- Neutral 3
- Disagree 4
- Strongly disagree 5

I am a believer in the idea that "every cloud has a silver lining".

- Strongly agree 1
- Agree 2
- Neutral 3
- Disagree 4
- Strongly disagree 5

I do not count on good things happening to me.

- Strongly agree 1
- Agree 2
- Neutral 3
- Disagree 4
- Strongly disagree 5

I'm optimistic about my health.

- Strongly egree 1
- Agree 2
- Neutral 3
- Disagree 4
- Strongly disagree 5

In terms of my health, I anticipate the worst.

- Strongly agree 1
- Agree 2
- Neutral 3
- Disagree 4
- Strongly disagree 5

Regarding my health, I look on the bright side of things.

- Strongly agree 1
- Agree 2
- Neutral 3
- Disagree 4
- Strongly disagree 5

If something about my health can go wrong, it will.

Strongly agree 1
Agree 2
Neutral 3
Disagree 4
Strongly disagree 5

Next there are a number of statements which represent a variety of opinions about how people view life. Please indicate how much you agree or disagree with each statement below by circling the appropriate number.

Many times I feel that we might just as well make many of our decisions by flipping a coin.

Strongly agree 1
Agree 2
Disagree 3
Strongly disagree 4

Getting a good job seems to be largely a matter of being lucky enough to be in the right place at the right time.

Strongly agree 1
Agree 2
Disagree 3
Strongly disagree 4

It is difficult for ordinary people to have much control over what politicians do in office.

Strongly agree 1
Agree 2
Disagree 3
Strongly disagree 4

It is not wise to plan too far ahead because most things turn out to be a matter of good or bad fortune anyhow.

Strongly agree 1
Agree 2
Disagree 3
Strongly disagree 4

When things are going well for me I consider it due to a run of good luck.

Strongly agree 1
Agree 2
Disagree 3
Strongly disagree 4

I have usually found that what is going to happen will happen regardless of my actions.

Strongly agree 1
Agree 2
Disagree 3
Strongly disagree 4

□ 27

□

□

□ 30

□

□

□ 33

Success is mostly a matter of getting good breaks.

Strongly agree 1
Agree 2
Disagree 3
Strongly disagree 4

There is not much use in worrying about things what will be, will be.

Strongly agree 1
Agree 2
Disagree 3
Strongly disagree 4

Success in dealing with people seems to be more a matter of the other person's moods and feelings at the time rather than one's own actions.

Strongly agree 1
Agree 2
Disagree 3
Strongly disagree 4

I think that life is mostly a gamble.

Strongly agree 1
Agree 2
Disagree 3
Strongly disagree 4

Many times I feel that I have little influence over the things that happen to me.

Strongly agree 1
Agree 2
Disagree 3
Strongly disagree 4

□ 36

□

□

□

□ 38

The following statements reflect various ways that people regard their health. Please indicate how much you agree or disagree with each statement below by circling the appropriate number.

If I get sick, it is my own behaviour which determines how soon I get well again.

- Strongly agree 1
- Agree 2
- Neutral 3
- Disagree 4
- Strongly disagree 5

39

I am in control of my health.

- Strongly agree 1
- Agree 2
- Neutral 3
- Disagree 4
- Strongly disagree 5

40

The main thing which affects my health is what I myself do.

- Strongly agree 1
- Agree 2
- Neutral 3
- Disagree 4
- Strongly disagree 5

If I take care of myself, I can avoid illness.

- Strongly agree 1
- Agree 2
- Neutral 3
- Disagree 4
- Strongly disagree 5

When I get sick I am to blame.

- Strongly agree 1
- Agree 2
- Neutral 3
- Disagree 4
- Strongly disagree 5

If I take the right actions, I can stay healthy.

- Strongly agree 1
- Agree 2
- Neutral 3
- Disagree 4
- Strongly disagree 5

44

Here are a number of words that describe different feelings and emotions. Please read each word and then circle the appropriate number next to that word to indicate to what extent you have felt this way **during the past month**.

1 = very slightly
2 = a little
3 = moderately
4 = quite a bit
5 = extremely

interested	1	2	3	4	5
distressed	1	2	3	4	5
excited	1	2	3	4	5
upset	1	2	3	4	5
strong	1	2	3	4	5
guilty	1	2	3	4	5
scared	1	2	3	4	5
hostile	1	2	3	4	5
enthusiastic	1	2	3	4	5
proud	1	2	3	4	5
irritable	1	2	3	4	5
alert	1	2	3	4	5
ashamed	1	2	3	4	5
inspired	1	2	3	4	5
nervous	1	2	3	4	5
determined	1	2	3	4	5
attentive	1	2	3	4	5
jittery	1	2	3	4	5
active	1	2	3	4	5
afraid	1	2	3	4	5

45 50 60

These next questions are about how **often** you have felt various emotions **during the past month**. For each question, please circle a number for the answer that comes closest to the way you have been feeling.

How often did you become nervous or jumpy when faced with excitement or unexpected situations during the past month?

- Always 1
- Very often 2
- Fairly often 3
- Sometimes 4
- Almost never 5
- Never 6

65

Did you feel depressed during the past month?

- Yes, to the point that I did not care about anything for days at a time 1
- Yes, very depressed almost every day 2
- Yes, quite depressed several times 3
- Yes, a little depressed now and then 4
- No, never felt depressed at all 5

☐ 66

How much of the time, during the past month, have you been a very nervous person?

- Always 1
- Very often 2
- Fairly often 3
- Sometimes 4
- Almost never 5
- Never 6

☐

During the past month, how much of the time have you felt tense or "high-strung"?

- Always 1
- Very often 2
- Fairly often 3
- Sometimes 4
- Almost never 5
- Never 6

☐

How much of the time, during the past month, have you felt downhearted and blue?

- Always 1
- Very often 2
- Fairly often 3
- Sometimes 4
- Almost never 5
- Never 6

☐

How much have you been bothered by nervousness, or your "nerves", during the past month?

- Extremely so, to the point where I could not take care of things 1
- Very much bothered 2
- Bothered quite a bit by nerves 3
- Bothered some, enough to notice 4
- Bothered just a little by nerves 5
- Not bothered at all by this 6

☐ 70

During the past month, how much of the time have you felt restless, fidgety, or impatient?

- Always 1
- Very often 2
- Fairly often 3
- Sometimes 4
- Almost never 5
- Never 6

☐ 71

During the past month, how much of the time have you been moody or brooded about things?

- All of the time 1
- Most of the time 2
- A good bit of the time 3
- Some of the time 4
- A little of the time 5
- None of the time 6

☐ 72

During the past month, how often did you get rattled, upset, or flustered?

- Always 1
- Very often 2
- Fairly often 3
- Sometimes 4
- Almost never 5
- Never 6

☐

During the past month, have you been anxious or worried?

- Yes, extremely so, to the point of being almost sick 1
- Yes, very much so 2
- Yes, quite a bit 3
- Yes, some, enough to bother me 4
- Yes, a little bit 5
- No, not at all 6

☐

How often during the past month did you find yourself having difficulty trying to calm down?

- Always 1
- Very often 2
- Fairly often 3
- Sometimes 4
- Almost never 5
- Never 6

☐

During the past month, how much of the time have you been in low or very low spirits?

- All of the time 1
- Most of the time 2
- A good bit of the time 3
- Some of the time 4
- A little of the time 5
- None of the time 6

☐

Next, we would like you to consider how satisfied you are with your life. Please circle the number that best describes this for you.

How do you feel about your life as a whole?

- Terrible 1
- Very dissatisfied 2
- Mostly dissatisfied 3
- Mixed, about equally satisfied or dissatisfied 4
- Mostly satisfied 5
- Very satisfied 6
- Delighted 7

☐ 77

Read each of the following statements carefully and decide whether they are true (T) as applied to you or false (F) as applied to you. Please circle the appropriate letter at the end of each statement

I might as well give up because I can't make things better for myself.	T	F
I just don't get the breaks, and there is no reason to believe I will in the future.	T	F
When things are going badly I am helped by knowing they can't stay that way forever.	T	F
All I can see ahead of me is unpleasantness rather than pleasantness.	T	F
I don't expect to get what I really want.	T	F
I never get what I want so it's foolish to want anything.	T	F
It is very unlikely that I will get any real satisfaction in the future.	T	F
There's no use in really trying to get something I want because I probably won't get it.	T	F

The following questions ask about people in your life who give you help or support. Each question has two parts. For the first part, list all the people, apart from yourself, who you can count on for help or support in the way described. Give the person's initials and their relationship to you (there is an example below to refer to). Do not list more than one person next to each of the numbers beneath the question. For each question, if you have no support, put a tick beside the word "no one" but still rate your level of satisfaction. It is not necessary to provide nine sets of initials, however do not list *more* than nine per question.

For the second part, circle how satisfied you are with the overall (amount of) support you have. Please answer all questions as best you can.

EXAMPLE:

Who do you know who you can trust with information that could get you into trouble?

_____No one	(1) T N (brother)	(4) S N (father)	(7)	
	(2) L M (friend)	(5)	(8)	
	(3) R S (friend)	(6)	(9)	

How satisfied?

6-very satisfied | **5-fairly satisfied** (circled) | **4-a little satisfied** | **3-a little dissatisfied** | **2-fairly dissatisfied** | **1-very dissatisfied**

78

80

CARD 3

5

Who can you really count on to take your mind off your worries when you feel under stress?

_____No one	(1)	(4)	(7)
	(2)	(5)	(8)
	(3)	(6)	(9)

How satisfied?

6-very satisfied | 5-fairly satisfied | 4-a little satisfied | 3-a little dissatisfied | 2-fairly dissatisfied | 1-very dissatisfied

5

Who can you really rely on when you need help?

_____No one	(1)	(4)	(7)
	(2)	(5)	(8)
	(3)	(6)	(9)

How satisfied?

6-very satisfied | 5-fairly satisfied | 4-a little satisfied | 3-a little dissatisfied | 2-fairly dissatisfied | 1-very dissatisfied

10

With whom can you totally be yourself?

_____No one	(1)	(4)	(7)
	(2)	(5)	(8)
	(3)	(6)	(9)

How satisfied?

6-very satisfied | 5-fairly satisfied | 4-a little satisfied | 3-a little dissatisfied | 2-fairly dissatisfied | 1-very dissatisfied

Who will comfort you when you need it by holding you in their arms?

_____No one	(1)	(4)	(7)
	(2)	(5)	(8)
	(3)	(6)	(9)

How satisfied?

6-very satisfied | 5-fairly satisfied | 4-a little satisfied | 3-a little dissatisfied | 2-fairly dissatisfied | 1-very dissatisfied

15

241

Who accepts you totally, including your worst and best points?

_____No one (1) (4) (7)

(2) (5) (8)

(3) (6) (9)

How satisfied?

6-very satisfied	5-fairly satisfied	4-a little satisfied	3-a little dissatisfied	2-fairly dissatisfied	1-very dissatisfied

Who can you really count on to care about you, regardless of what is happening to you?

_____No one (1) (4) (7)

(2) (5) (8)

(3) (6) (9)

How satisfied?

6-very satisfied	5-fairly satisfied	4-a little satisfied	3-a little dissatisfied	2-fairly dissatisfied	1-very dissatisfied

Who can you count on to help you feel better when you are very upset?

_____No one (1) (4) (7)

(2) (5) (8)

(3) (6) (9)

How satisfied?

6-very satisfied	5-fairly satisfied	4-a little satisfied	3-a little dissatisfied	2-fairly dissatisfied	1-very dissatisfied

Who can really count on to support you in major decisions you make?

_____No one (1) (4) (7)

(2) (5) (8)

(3) (8) (9)

How satisfied?

6-very satisfied	5-fairly satisfied	4-a little satisfied	3-a little dissatisfied	2-fairly dissatisfied	1-very dissatisfied

These next two questions should be answered in exactly the same manner as those above. However, if appropriate you can include medical care givers in your list (i e doctor, physiotherapist, psychologist etc).

Who can you really count on to be understanding about your MS condition?

_____No one (1) (4) (7)

(2) (5) (8)

(3) (6) (9)

How satisfied?

6-very satisfied	5-fairly satisfied	4-a little satisfied	3-a little dissatisfied	2-fairly dissatisfied	1-very dissatisfied

Who can you really count on to assist you with problems that arise from your MS condition?

_____No one (1) (4) (7)

(2) (5) (8)

(3) (6) (9)

How satisfied?

6-very satisfied	5-fairly satisfied	4-a little satisfied	3-a little dissatisfied	2-fairly dissatisfied	1-very dissatisfied

The following section focuses on your relationship with your spouse or partner. If you do not have a spouse or partner please tick the not applicable box, and do not complete this section.

Not applicable ☐

During the <u>past month</u>, how would you describe your intimate relationship with your partner? Please circle the number which best describes how you have experienced each aspect of your relationship.

1 = excellent
2 = good
3 = satisfactory
4 = poor
5 = terrible

The emotional aspects .... (your feelings for your partner)	1	2	3	4	5
The physical aspects .... (kissing, cuddling, caressing)	1	2	3	4	5
The sexual aspects .... (sexual behaviour such as intercourse)	1	2	3	4	5

In this final part of the questionnaire we would like to find out some information about your Multiple Sclerosis condition, and about your health in general.

Below is a list of common MS symptoms. First, please indicate **how often** each symptom has been a problem for you during the last **month**, by circling the most appropriate number. Second, please rate **how bad** (intense) each symptom was when it was at its **worst**. Circle the number which best represents your experience of the symptom.

1 = never
2 = at least once a month
3 = at least once a week
4 = at teast once a day
5 = constantly

Balance problems (unsteadiness) 1 2 3 4 5

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely intense

Spasticity 1 2 3 4 5
(involuntary muscle contractions or muscle spasms)

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely intense

Tremor (shaking or quivering) 1 2 3 4 5

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely intense

Weakness 1 2 3 4 5
(lack of strength, generally, or in any part of your body)

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely intense

Fatigue (tiredness) 1 2 3 4 5

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely intense

Bladder problems 1 2 3 4 5

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely intense

Bowel problems 1 2 3 4 5

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely intense

Pain 1 2 3 4 5

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely intense

Speech problems 1 2 3 4 5

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely intense

Visual disturbances (problems with your sight) 1 2 3 4 5

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely intense

Numbness (can't feel or move part of your body) 1 2 3 4 5

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely intense

Pressure sores 1 2 3 4 5

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely intense

Listed below are some activities that most people come across in their daily living situation. Please indicate to what extent you are able to carry out these activities by circling the number that best describes your present ability.

Eating

You are independent (you can use fork, knife, cut food, spread butter etc) 1
You need help (assistance with such things as cutting, spreading butter etc) 2
You are dependent (you need to be fed) 3

Grooming

You are independent (you can do all personal activities, such as combing hair, shaving, brushing teeth etc) 1
You are dependent (you need some help with your grooming) 2

Bowels

You are fully continent 1
You have an occasional accident (less than one a week) 2
You are incontinent 3

Bladder

You are fully continent (and able to use catheter if needed) 1
You have an occasional accident (less than one a week) 2
You are incontinent 3

Dressing

You are independent (you do not need any help dressing) 1
You need some assistance 2
You are dependent (you need major help) 3

Chair/bed transfer

You are independent (you do not need any help) 1
You need minimal help (you need verbal assistance or minor help) 2
You are able to sit but need major assistance 3
You are dependent (you need to be lifted by others and are unable to sit) 4

Toilet

You are independent (you can get on and off the toilet, flush the toilet etc.) 1
You need minor help with such things as balancing or toilet paper 2
You are dependent (you need major assistance) 3

☐ 73

☐☐

☐

☐

☐

☐

☐ 80

CARD 4

☐

☐ 2

Mobility

You are independent (you can walk unaided, or using any aid other than a rolling walker) 1
You need minimal help to walk (verbal or minor assistance) 2
You are independent in a wheelchair (you can negotiate corners alone) 3
You are dependent (you need to be wheeled by another) 4

Stairs

You are independent (you do not require any help) 1
You need some assistance (verbal or minor help) 2
You are unable to negotiate stairs (you require a lift) 3

Bathing

You are independent (you can get in and out of bath or shower, and wash all over) 1
You are dependent (you need some help) 2

How would you rate your <u>overall</u> health at the present time? (Please circle the number that best describes this.)

Very much better than last month 1
Better than last month 2
About the same as last month 3
Worse than last month 4
Very much worse than last month 5

Thank you very much for completing this questionnaire. We greatly appreciate the time you have given in order to take part in this study. We will be mailing a summary of our findings out to you as soon as we have them available.

If you have any comments about this study, or any of the questions please write them over the page.

☐ 3

☐

☐

☐

☐ 7

244

ID

ID

MINI MENTAL STATE

5

Score

Orientation

( ) What is the (year) (season) (month) (date) (day)? (5 points)

( ) Where are we? (~~county~~) (town)
(4 points) (street number & name)

Registration

( ) Name 3 objects: 1 second to say each. Then ask the patient to repeat all three after you have said them. 1 point for each correct. Then repeat them until he learns them. Count trials and record _____.
(3 points)

Attention and Calculation

( ) Serial 7's. 1 point for each correct. Stop at 5 answers. and spell "world" backwards. (Number correct equals letters before first mistake - i.e., d l o r w = 2 correct).
(5 points) USE BEST SCORE

Recall

( ) Ask for the objects above. 1 point for each correct. (3 points)

10

Language Tests

( ) name - pencil, watch (2 points)

( ) repeat - no ifs, ands or buts (1 point)

( ) follow a 3 stage command: "Take the paper in your right hand, fold it in half, and put it on the floor." (3 points)

or adapt to suit

Score

obey the following:

( ) CLOSE YOUR EYES. (1 point)

( ) Tell me a sentence (spontaneously) (1 point)

TOTAL SCORE (out of 28 points) _____

17

MULTIPLE SCLEROSIS QUESTIONNAIRE

CARD 1

☐☐

new ID

☐☐

old ID

☐

TIME

In this questionnaire we will ask you a number of questions about your health, the sorts of experiences you have and how you feel about them. This is a shorter questionnaire than the first one you completed. If some of the questions seem familiar to you, it is because you have come across them before in a previous questionnaire. However, it is important for our purposes that we ask these questions again.

We hope that you are finding taking part is this study to be an interesting and enjoyable experience. Your ongoing participation in this study is very important to us.

In the first set of questions we want to ask about the hassles you have experienced this last month. Hassles are irritants that can range from minor annoyances to fairly major pressures, problems, or difficulties. Hassles can occur few or many times.

Below is a list of some things that can be considered hassles in day-to-day life. During the course of the last month some of these things will have been a hassle for you. Please think how much of a hassle each of these things was for you **during the last month**. Indicate on the right-hand side of the page (under "HASSLES") how much of a hassle each statement was by circling the appropriate number.

HASSLES
0 = Not at all or not applicable
1 = Somewhat
2 = Quite a bit
3 = A great deal

Remember you must circle one answer for every item.

Your child(ren) _____ 0 1 2 3

Your parents or parents-in-law _____ 0 1 2 3

Other relative(s) _____ 0 1 2 3

Your spouse _____ 0 1 2 3

Time spent with family _____ 0 1 2 3

Health or well-being of a family member _____ 0 1 2 3

Intimacy _____ 0 1 2 3

Family related obligations _____ 0 1 2 3

☐ ☐ ☐ ☐ ☐ 10 ☐ ☐ ☐ 13

HASSLES
0 = Not at all or not applicable
1 = Somewhat
2 = Quite a bit
3 = A great deal

Your friend(s) _____ 0 1 2 3

Fellow workers _____ 0 1 2 3

Clients, customers, patients etc _____ 0 1 2 3

Your supervisor or employer _____ 0 1 2 3

The nature of your work _____ 0 1 2 3

Your work load _____ 0 1 2 3

Your job security _____ 0 1 2 3

Meeting deadlines or goals on the job _____ 0 1 2 3

Enough money for necessities (e g food, clothing, housing, health care, taxes) _____ 0 1 2 3

Enough money for education _____ 0 1 2 3

Enough money for emergencies _____ 0 1 2 3

Enough money for extras (e g vacations, recreation, entertainment) _____ 0 1 2 3

Financial care for someone who doesn't live with you _____ 0 1 2 3

Investments _____ 0 1 2 3

Your smoking _____ 0 1 2 3

Your drinking _____ 0 1 2 3

Mood-altering drugs _____ 0 1 2 3

Your physical appearance _____ 0 1 2 3

Contraception _____ 0 1 2 3

Exercise(s) _____ 0 1 2 3

Your medical care _____ 0 1 2 3

Sex _____ 0 1 2 3

Your health _____ 0 1 2 3

☐ 15 ☐☐☐☐☐☐☐☐☐☐ 20 ☐☐☐☐☐☐☐☐☐☐ 30 ☐☐☐☐☐☐☐☐☐☐

HASSLES
0 = Not at all or not applicable
1 = Somewhat
2 = Quite a bit
3 = A great deal

Your physical abilities _____ 0 1 2 3

The weather _____ 0 1 2 3

News events _____ 0 1 2 3

Your environment (e g quality of air, noise level, trees and greenery _____ 0 1 2 3

Political or social issues _____ 0 1 2 3

Your neighbourhood (e g neighbours, the area you live in)_____ 0 1 2 3

Conserving (gas, electricity, water, petrol, etc)_____ 0 1 2 3

Pets_____ 0 1 2 3

Cooking_____ 0 1 2 3

Housework _____ 0 1 2 3

Home repairs_____ 0 1 2 3

Yardwork_____ 0 1 2 3

Car maintenance_____ 0 1 2 3

Taking care of paperwork (e g paying bills, filling out forms)_____ 0 1 2 3

Home entertainment (e g T V, music, reading)_____ 0 1 2 3

Amount of free time_____ 0 1 2 3

Recreation and entertainment outside the home (e g movies, sport, eating out, walking) _____ 0 1 2 3

Eating (at home) _____ 0 1 2 3

Church or community organisations _____ 0 1 2 3

Legal matters _____ 0 1 2 3

Being organised _____ 0 1 2 3

Social commitments _____ 0 1 2 3

37 40 50 58

Now that we have considered your everyday hassles, we would like you to list any major events that have happened to you in the past month. Next, please indicate (circle) to what extent each event has influenced your life. If nothing major has taken place in your life during the past month please leave this section blank.

Event	not at all	somewhat	quite a bit	a great deal
_____	0	1	2	3
_____	0	1	2	3
_____	0	1	2	3

59 60

Next, we want you to consider how satisfied you are with your life. Please circle the number that best describes this for you.

How you do feel about your life as a whole?

Terrible 1
Very dissatisfied 2
Mostly dissatisfied 3
Mixed about equally satisfied or dissatisfied 4
Mostly satisfied 5
Very satisfied 6
Delighted 7

Here are a number of words that describe different feelings and emotions. Please read each word and then circle the appropriate number next to that word to indicate to what extent you have felt this way during the past month.

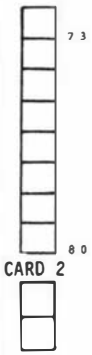
1 = very slightly
2 = a little
3 = moderately
4 = quite a bit
5 = extremely

interested	1	2	3	4	5
distressed	1	2	3	4	5
excited	1	2	3	4	5
upset	1	2	3	4	5
strong	1	2	3	4	5
guilty	1	2	3	4	5
scared	1	2	3	4	5
hostile	1	2	3	4	5
enthusiastic	1	2	3	4	5
proud	1	2	3	4	5

72

1 = very slightly
2 = a little
3 = moderately
4 = quite a bit
5 = extremely

irritable	1	2	3	4	5
alert	1	2	3	4	5
ashamed	1	2	3	4	5
inspired	1	2	3	4	5
nervous	1	2	3	4	5
determined	1	2	3	4	5
attentive	1	2	3	4	5
jittery	1	2	3	4	5
active	1	2	3	4	5
afraid	1	2	3	4	5



These next questions are about how **often** you have felt various emotions **during the past month**. For each question, please circle a number for the answer that comes closest to the way you have been feeling.

How often did you become nervous or jumpy when faced with excitement or unexpected situations during the past month?

- Always 1
- Very often 2
- Fairly often 3
- Sometimes 4
- Almost never 5
- Never 6

Did you feel depressed during the past month?

- Yes, to the point that I did not care about anything for days at a time 1
- Yes, very depressed almost every day 2
- Yes, quite depressed several times 3
- Yes, a little depressed now and then 4
- No, never felt depressed at all 5

How much of the time, during the past month, have you been a very nervous person?

- Always 1
- Very often 2
- Fairly often 3
- Sometimes 4
- Almost never 5
- Never 6

During the past month, how much of the time have you felt tense or "high-strung"?

- Always 1
- Very often 2
- Fairly often 3
- Sometimes 4
- Almost never 5
- Never 6

How much of the time, during the past month, have you felt downhearted and blue?

- Always 1
- Very often 2
- Fairly often 3
- Sometimes 4
- Almost never 5
- Never 6

How much have you been bothered by nervousness, or your "nerves", during the past month?

- Extremely so, to the point where I could not take care of things 1
- Very much bothered 2
- Bothered quite a bit by nerves 3
- Bothered some, enough to notice 4
- Bothered just a little by nerves 5
- Not bothered at all by this 6

During the past month, how much of the time have you felt restless, fidgety, or impatient?

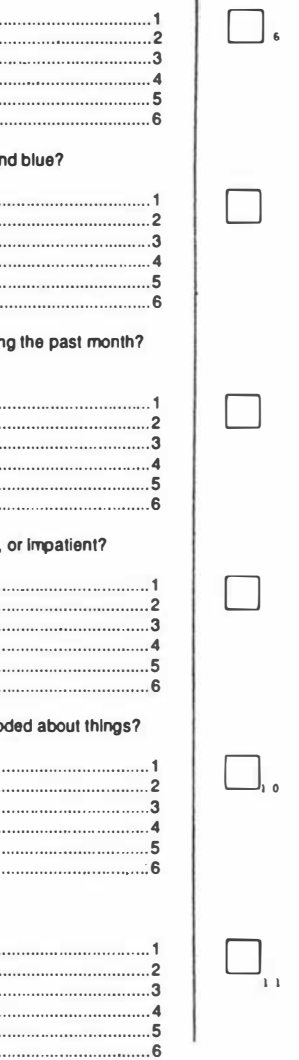
- Always 1
- Very often 2
- Fairly often 3
- Sometimes 4
- Almost never 5
- Never 6

During the past month, how much of the time have you been moody or brooded about things?

- All of the time 1
- Most of the time 2
- A good bit of the time 3
- Some of the time 4
- A little of the time 5
- None of the time 6

During the past month, how often did you get rattled, upset, or flustered?

- Always 1
- Very often 2
- Fairly often 3
- Sometimes 4
- Almost never 5
- Never 6



During the past month, have you been anxious or worried?

- Yes, extremely so, to the point of being almost sick 1
- Yes, very much so 2
- Yes, quite a bit 3
- Yes, some, enough to bother me 4
- Yes, a little bit 5
- No, not at all 6

How often during the past month did you find yourself having difficulty trying to calm down?

- Always 1
- Very often 2
- Fairly often 3
- Sometimes 4
- Almost never 5
- Never 6

During the past month, how much of the time have you been in low or very low spirits?

- All of the time 1
- Most of the time 2
- A good bit of the time 3
- Some of the time 4
- A little of the time 5
- None of the time 6

Next, we would like you to consider how satisfied you are with your life. Please circle the number that best describes this for you.

How do you feel about your life as a whole?

- Terrible 1
- Very dissatisfied 2
- Mostly dissatisfied 3
- Mixed, about equally satisfied or dissatisfied 4
- Mostly satisfied 5
- Very satisfied 6
- Delighted 7

Read each of the following statements carefully and decide whether they are true (T) as applied to you or false (F) as applied to you. Please circle the appropriate letter at the end of each statement

I might as well give up because I can't make things better for myself.	T	F
I just don't get the breaks, and there is no reason to believe I will in the future.	T	F
When things are going badly I am helped by knowing they can't stay that way forever.	T	F
All I can see ahead of me is unpleasantness rather than pleasantness.	T	F
I don't expect to get what I really want.	T	F

I never get what I want so it's foolish to want anything.	T	F
It is very unlikely that I will get any real satisfaction in the future.	T	F
There's no use in really trying to get something I want because I probably won't get it.	T	F

In this final part of the questionnaire we would like to find out some information about your Multiple Sclerosis condition, and about your health in general.

Below is a list of common MS symptoms. First, please indicate <u>how often</u> each symptom has been a problem for you during the last <u>month</u>, by circling the most appropriate number. Second, please rate <u>how bad</u> (intense) each symptom was when it was at its <u>worst</u>. Circle the number which best represents your experience of the symptom.

1 = never
2 = at least once a month
3 = at least once a week
4 = at least once a day
5 = constantly

Balance problems (unsteadiness) 1 2 3 4 5

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all — extremely intense

Spasticity 1 2 3 4 5
(involuntary muscle contractions or muscle spasms)

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all — extremely intense

Tremor (shaking or quivering) 1 2 3 4 5

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all — extremely intense

1 = never
2 = at least once a month
3 = at least once a week
4 = at least once a day
5 = constantly

Weakness 1 2 3 4 5
(lack of strength, generally, or in any part of your body)

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely intense

Fatigue (tiredness) 1 2 3 4 5

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely intense

Bladder problems 1 2 3 4 5

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely intense

Bowel problems 1 2 3 4 5

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely intense

Pain 1 2 3 4 5

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely intense

Speech problems 1 2 3 4 5

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely intense

33

40

50

1 = never
2 = at least once a month
3 = at least once a week
4 = at least once a day
5 = constantly

Visual disturbances (problems with your sight) 1 2 3 4 5

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely intense

Numbness (can't feel or move part of your body) 1 2 3 4 5

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely intense

Pressure sores 1 2 3 4 5

How intense?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely intense

Listed below are some activities that most people come across in their daily living situation. Please indicate to what extent you are able to carry out these activities by circling the number that best describes your present ability.

Eating

You are independent (you can use fork, knife, cut food, spread butter etc) 1
You need help (assistance with such things as cutting, spreading butter etc) 2
You are dependent (you need to be fed) 3

Grooming

You are independent (you can do all personal activities, such as combing hair, shaving, brushing teeth etc) 1
You are dependent (you need some help with your grooming) 2

Bowels

You are fully continent 1
You have an occasional accident (less than one a week) 2
You are incontinent 3

51

60

Bladder

You are fully continent (and able to use catheter if needed) 1
You have an occasional accident (less than one a week) 2
You are incontinent 3

Dressing

You are independent (you do not need any help dressing) 1
You need some assistance 2
You are dependent (you need major help) 3

Chair/bed transfer

You are independent (you do not need any help) 1
You need minimal help (you need verbal assistance or minor help) 2
You are able to sit but need major assistance 3
You are dependent (you need to be lifted by others and are unable to sit) 4

Toilet

You are independent (you can get on and off the toilet, flush the toilet etc.) 1
You need minor help with such things as balancing or toilet paper 2
You are dependent (you need major assistance) 3

Mobility

You are independent (you can walk unaided, or using any aid other than a rolling walker) 1
You need minimal help to walk (verbal or minor assistance) 2
You are independent in a wheelchair (you can negotiate corners alone) 3
You are dependent (you need to be wheeled by another) 4

Stairs

You are independent (you do not require any help) 1
You need some assistance (verbal or minor help) 2
You are unable to negotiate stairs (you require a lift) 3

Bathing

You are independent (you can get in and out of bath or shower, and wash all over) 1
You are dependent (you need some help) 2

How would you rate your <u>overall</u> health at the present time? (Please circle the number that best describes this.)

Very much better than last month 1
Better than last month 2
About the same as last month 3
Worse than last month 4
Very much worse than last month 5

Thank you very much for completing this questionnaire. We greatly appreciate the time you have given in order to take part in this study. We will be mailing a summary of our findings out to you as soon as we have them available.

If you have any comments about this study, or any of the questions please write them over the page.

☐ 63

☐

☐

☐

☐

☐

☐

☐ 70

☐ 71

CARD 1

PHYSICAL EXAMINATION SUMMARY SHEET

new ID

old ID

T

Is this person taking any medications? yes☐ no☐

If applicable list medications and reasons for taking.

Does this person have any chronic health condition other than MS?

yes☐ no☐

If so, has this posed any special problem in the last month?

yes☐ no☐

Notes:

KURTZKE SCALES

Disability status (rate 0 to 10) . . . . . ☐ 13

Functional systems

Pyramidal (rate 0 to 6, 7 unknown) . . . . . ☐

Cerebellar (rate 0 to 5, 7 unknown) . . . . . ☐

Brainstem (rate 0 to 5, 7 unknown) . . . . . ☐

Sensory (rate 0 to 6, 7 unknown) . . . . . ☐

Bowel and bladder (rate 0 to 5, 7 unknown) . . . ☐

Visual (rate 0 to 6, 7 unknown) . . . . . ☐ 16

FUNCTIONAL INDEPENDENCE MEASURE
(all ratings 1 to 7)

Self care

Feeding	☐	☐ 17
Grooming	☐	☐
Bathing	☐	☐
Dressing-upper body	☐	☐ 20
Dressing-lower body	☐	☐
Toileting	☐	☐

Sphincter Control

Bladder management	☐	☐
Bowel management	☐	☐

Mobility

Transfer:

Bed, chair, w/chair	☐	☐
Toilet	☐	☐
Tub, shower	☐	☐

Locomotion

Walk, wheel chair (W, C, or B)	☐☐	☐
Stairs	☐	☐ 30

Communication

Comprehension . . . . . ☐☐ 31
(A, V or B)

Expression . . . . . ☐☐
(V, N or B)

Social Cognition

Social interaction . . . . . ☐

Problem Solving . . . . . ☐

Memory . . . . . ☐

(IGNORE AT TIME 1)
How would you best describe this person's <u>overall</u> health at the present time? (circle a number)

Very much better than last month	1
Better than last month	2
About the same as last month	3
Worse than last month	4
Very much worse than last month	5

☐ 38

Notes:

MULTIPLE SCLEROSIS QUESTIONNAIRE

CARD 1

New ID

Old ID

D/M
Date

In this interview, we want to find out what sort of experiences you have and how you feel about them. We will be asking you a number of questions and hope that you will answer them carefully and honestly. Keep in mind that there are no right or wrong answers.

Occasionally you may think that we have already covered a topic, and have asked the same kind of question with a difference in wording. You will be right. However, it is important for our purposes that we ask these questions.

Your participation in this study is very important to us. We hope you will find the experience interesting and enjoyable.

The following statements reflect various ways that people regard their health. Please indicate how much you agree or disagree with each statement below by circling the appropriate number.

If I get sick, it is my own behaviour which determines how soon I get well again.

Strongly agree 1
Agree 2
Neutral 3
Disagree 4
Strongly disagree 5

I am in control of my health.

Strongly agree 1
Agree 2
Neutral 3
Disagree 4
Strongly disagree 5

10

The main thing which affects my health is what I myself do.

Strongly agree 1
Agree 2
Neutral 3
Disagree 4
Strongly disagree 5

If I take care of myself, I can avoid illness.

Strongly agree 1
Agree 2
Neutral 3
Disagree 4
Strongly disagree 5

When I get sick I am to blame.

Strongly agree 1
Agree 2
Neutral 3
Disagree 4
Strongly disagree 5

13

If I take the right actions, I can stay healthy.

Strongly agree 1
Agree 2
Neutral 3
Disagree 4
Strongly disagree 5

14

Here are a number of statements about how people experience life. Please indicate to what extent you agree or disagree with each statement by circling the appropriate number.

In uncertain times, I expect the best.

Strongly agree 1
Agree 2
Neutral 3
Disagree 4
Strongly disagree 5

If something can go wrong for me it will.

Strongly agree 1
Agree 2
Neutral 3
Disagree 4
Strongly disagree 5

I look on the bright side of things.

Strongly agree 1
Agree 2
Neutral 3
Disagree 4
Strongly disagree 5

I'm optimistic about my future.

Strongly agree 1
Agree 2
Neutral 3
Disagree 4
Strongly disagree 5

I do not expect things to go my way.

Strongly agree 1
Agree 2
Neutral 3
Disagree 4
Strongly disagree 5

Things do not work out the way I want them to.

Strongly agree 1
Agree 2
Neutral 3
Disagree 4
Strongly disagree 5

20

I am a believer in the idea that "every cloud has a silver lining".

Strongly agree 1
Agree 2
Neutral 3
Disagree 4
Strongly disagree 5

21

I do not count on good things happening to me.

Strongly agree 1
Agree 2
Neutral 3
Disagree 4
Strongly disagree 5

I'm optimistic about my health.

Strongly egree 1
Agree 2
Neutral 3
Disagree 4
Strongly disagree 5

In terms of my health, I anticipate the worst.

Strongly agree 1
Agree 2
Neutral 3
Disagree 4
Strongly disagree 5

Regarding my health, I look on the bright side of things.

Strongly agree 1
Agree 2
Neutral 3
Disagree 4
Strongly disagree 5

If something about my health can go wrong, it will.

Strongly agree 1
Agree 2
Neutral 3
Disagree 4
Strongly disagree 5

26

Next there are a number of statements which represent a variety of opinions about how people view life. Please indicate how much you agree or disagree with each statement below by circling the appropriate number.

Many times I feel that we might just as well make many of our decisions by flipping a coin.

Strongly agree 1
Agree 2
Disagree 3
Strongly disagree 4

27

Getting a good job seems to be largely a matter of being lucky enough to be in the right place at the right time.

Strongly agree 1
Agree 2
Disagree 3
Strongly disagree 4

It is difficult for ordinary people to have much control over what politicians do in office.

Strongly agree 1
Agree 2
Disagree 3
Strongly disagree 4

It is not wise to plan too far ahead because most things turn out to be a matter of good or bad fortune anyhow.

Strongly agree 1
Agree 2
Disagree 3
Strongly disagree 4

30

When things are going well for me I consider it due to a run of good luck.

Strongly agree 1
Agree 2
Disagree 3
Strongly disagree 4

I have usually found that what is going to happen will happen regardless of my actions.

Strongly agree 1
Agree 2
Disagree 3
Strongly disagree 4

Success is mostly a matter of getting good breaks.

Strongly agree 1
Agree 2
Disagree 3
Strongly disagree 4

There is not much use in worrying about things what will be, will be.

Strongly agree 1
Agree 2
Disagree 3
Strongly disagree 4

34

Success in dealing with people seems to be more a matter of the other person's moods and feelings at the time rather than one's own actions.

Strongly agree 1
Agree 2
Disagree 3
Strongly disagree 4

35

I think that life is mostly a gamble.

Strongly agree 1
Agree 2
Disagree 3
Strongly disagree 4

Many times I feel that I have little influence over the things that happen to me.

Strongly agree 1
Agree 2
Disagree 3
Strongly disagree 4

The next section asks questions about the way in which you view your life. For each of the following statements, circle the number that would be most nearly true for you. Note that the numbers always extend from one extreme to another. "Neutral" implies no judgement either way. Try to use number 4 **as little** as possible.

In life I have:

1 2 3 4 5 6 7
(neutral)

no goals or aims at all — very clear goals and aims

My personal existence is:

1 2 3 4 5 6 7
(neutral)

utterly meaningless without purpose — very purposeful and meaningful

If I could choose, I would:

1 2 3 4 5 6 7
(neutral)

prefer never to have been born — like nine more lives just like this one

40

After retiring, I would:

7 6 5 4 3 2 1
(neutral)

do some of the exciting things I have always wanted to — loaf completely the rest of my life

41

In achieving life goals I have:

1 2 3 4 5 6 7
(neutral)

made no progress whatever — progressed to complete fulfilment

42

If I should die today, I would feel that my life has been:

7 6 5 4 3 2 1
(neutral)

very worthwhile — completely worthless

In thinking of my life, I:

1 2 3 4 5 6 7
(neutral)

often wonder why I exist — always see a reason for my being here

As I view the world in relation to my life, the world:

1 2 3 4 5 6 7
(neutral)

completely confuses me — fits meaningfully

I am a:

1 2 3 4 5 6 7
(neutral)

very irresponsible person — very responsible person

With regard to death, I am:

7 6 5 4 3 2 1
(neutral)

prepared and unafraid — unprepared and frightened

With regard to suicide, I have:

1 2 3 4 5 6 7
(neutral)

thought of it seriously as a way out — never given it a second thought

I regard my ability to find a meaning, purpose, or mission in life as:

7 6 5 4 3 2 1
(neutral)

very great — practically none

49

I have discovered:

1 2 3 4 5 6 7
(neutral)

no mission or purpose in life — clear-cut goals and a satisfying life purpose

50

The following section focuses on your relationship with your spouse or partner. If you do not have a spouse or partner please tick the not applicable box, and do not complete this section.

Not applicable ☐

During the **past month**, how would you describe your intimate relationship with your partner? Please circle the number which best describes how you have experienced each aspect of your relationship.

1 = excellent
2 = good
3 = satisfactory
4 = poor
5 = terrible

The emotional aspects 1 2 3 4 5
(your feelings for your partner)

The physical aspects 1 2 3 4 5
(kissing, cuddling, caressing)

The sexual aspects 1 2 3 4 5
(sexual behaviour such as intercourse)

54

The following questions ask about people in your life who give you help or support. Each question has two parts. **For the first part**, list all the people, apart from yourself, who you can count on for help or support in the way described. Give the person's initials and their relationship to you (there is an example below to refer to). Do not list more than one person next to each of the numbers beneath the question. For each question, if you have no support, put a tick beside the word "no one" but still rate your level of satisfaction. It is not necessary to provide nine sets of initials, however do not list *more* than nine per question.

For the second part, circle how satisfied you are with the overall (amount of) support you have. Please answer all questions as best you can.

EXAMPLE:

Who do you know who you can trust with information that could get you into trouble?

____No one	(1) T N	(brother)	(4) S N (father)	(7)
	(2) L M	(friend)	(5)	(8)
	(3) R S	(friend)	(6)	(9)

How satisfied?

6-very satisfied | **5-fairly satisfied** | **4-a little satisfied** | **3-a little dissatisfied** | **2-fairly dissatisfied** | **1-very dissatisfied**

Who can you really count on to take your mind off your worries when you feel under stress?

____No one	(1)	(4)	(7)
	(2)	(5)	(8)
	(3)	(6)	(9)

55

How satisfied?

6-very satisfied | 5-fairly satisfied | 4-a little satisfied | 3-a little dissatisfied | 2-fairly dissatisfied | 1-very dissatisfied

Who can you really rely on when you need help?

____No one	(1)	(4)	(7)
	(2)	(5)	(8)
	(3)	(6)	(9)

How satisfied?

6-very satisfied | 5-fairly satisfied | 4-a little satisfied | 3-a little dissatisfied | 2-fairly dissatisfied | 1-very dissatisfied

60

With whom can you totally be yourself?

____No one	(1)	(4)	(7)
	(2)	(5)	(8)
	(3)	(6)	(9)

How satisfied?

6-very satisfied | 5-fairly satisfied | 4-a little satisfied | 3-a little dissatisfied | 2-fairly dissatisfied | 1-very dissatisfied

Who will comfort you when you need it by holding you in their arms?

____No one	(1)	(4)	(7)
	(2)	(5)	(8)
	(3)	(6)	(9)

How satisfied?

6-very satisfied | 5-fairly satisfied | 4-a little satisfied | 3-a little dissatisfied | 2-fairly dissatisfied | 1-very dissatisfied

66

Who accepts you totally, including your worst and best points?

_____No one (1) (4) (7)

(2) (5) (8)

(3) (6) (9)

How satisfied?

6-very satisfied | 5-fairly satisfied | 4-a little satisfied | 3-a little dissatisfied | 2-fairly dissatisfied | 1-very dissatisfied

Who can you really count on to care about you, regardless of what is happening to you?

_____No one (1) (4) (7)

(2) (5) (8)

(3) (6) (9)

How satisfied?

6-very satisfied | 5-fairly satisfied | 4-a little satisfied | 3-a little dissatisfied | 2-fairly dissatisfied | 1-very dissatisfied

Who can you count on to help you feel better when you are very upset?

_____No one (1) (4) (7)

(2) (5) (8)

(3) (6) (9)

How satisfied?

6-very satisfied | 5-fairly satisfied | 4-a little satisfied | 3-a little dissatisfied | 2-fairly dissatisfied | 1-very dissatisfied

Who can really count on to support you in major decisions you make?

_____No one (1) (4) (7)

(2) (5) (8)

(3) (6) (9)

How satisfied?

6-very satisfied | 5-fairly satisfied | 4-a little satisfied | 3-a little dissatisfied | 2-fairly dissatisfied | 1-very dissatisfied

67 70 78

These next two questions should be answered in exactly the same manner as those above. However, if appropriate you can include medical care givers in your list (i e doctor, physiotherapist, psychologist etc).

Who can you really count on to be understanding about your MS condition?

_____No one (1) (4) (7)

(2) (5) (8)

(3) (6) (9)

How satisfied?

6-very satisfied | 5-fairly satisfied | 4-a little satisfied | 3-a little dissatisfied | 2-fairly dissatisfied | 1-very dissatisfied

Who can you really count on to assist you with problems that arise from your MS condition?

_____No one (1) (4) (7)

(2) (5) (8)

(3) (6) (9)

How satisfied?

6-very satisfied | 5-fairly satisfied | 4-a little satisfied | 3-a little dissatisfied | 2-fairly dissatisfied | 1-very dissatisfied

Thank you very much for completing this questionnaire. We greatly appreciate the time you have given in order to take part in this study. We will be mailing a summary of our findings out to you as soon as we have them available.

If you have any comments about this study, or any of the questions please write them over the page.

79 80 CARD 2 1 5

APPENDIX D: ETHICAL CONSIDERATIONS FOR STUDY

ETHICAL CONSIDERATIONS

This project was conducted within the ethical guidelines of the New Zealand Psychological Society. Every care was taken to minimize risk of physical or mental harm to the participants. Ethical issues and related procedures are briefly discussed below:

Informed consent

Potential participants were fully informed about the study and their rights. Consent forms, outlining the researcher's responsibilities and providing relevant information, were signed by both the participant and the researcher. Participants involved in the longitudinal phase of the study, completed a second consent form. They were clearly informed of their right to withdraw from the study at any time.

Confidentiality

All questionnaires were identified by code number. A master list, linking names to code numbers, was available only to the researcher and her supervisors. The physician kept normal hospital records on all physical examinations. The researcher only had access to summary sheets (identified by code number) with information pertinent to the study. The data provided by the questionnaires was not given to the physician. For publication purposes, where cases are discussed, care will be taken to insure that individuals cannot be identified.

Medical issues

The physical examination was a completely routine neurological examination of the person's multiple sclerosis condition. It did not include intrusive tests of any sort. Prior to 1993, people with MS were normally examined by a physician at the Rehabilitation Unit about once a year. The examinations for this study required

similar procedures, but occurred more frequently. Any medical condition that was discovered during the examination (whether related to MS or not) was disclosed to the person, and all usual procedures for treatment and referrals were followed. The physician wrote to the general practitioner (GP) of every longitudinal participant, to inform them that he was examining (and possibly treating) their patient during the course of the research project.

Dependency issues

When participating in a longitudinal study, some people may become dependent on having regular contact with the researcher or physician. Individuals who required attention after the study finished were either contacted by the researcher or redirected to an appropriate source. The researcher had previous experience dealing with these sorts of issues while undertaking a community based project. Further, she has training and experience in the counselling and clinical area.

Psychological issues

None of the measures used in the study have been validated as diagnostic instruments. Therefore, the researcher is unable to make a clinical assessment of a participant based on information provided in his or her questionnaire(s). Care has been taken in the development of the questionnaire to select items that are unlikely to elicit strong reactions or distress from the respondent. However, if a participant showed signs of psychological distress, this was discussed with the person, and if appropriate followed up with a referral. All conversations with participants were held in strict confidence.

APPENDIX E: INTERCORRELATION MATRICES

Table E-1. *Intercorrelations of all Cross-sectional Variables (N=45)*

Variables	LE	HASS	SYMPFR	SYMIN	ADL	SHC
HASS	.2428					
SYMFR	-.0680	.1389				
SYMIN	-.1236	.3081*	.8038**			
ADL	.2238	.1274	-.4030**	-.5096**		
SHC	.1194	.1635	.0439	-.0181	-.0385	
HP	-.1298	-.1186	.1386	.0653	.0071	-.0546
ANX	.3276*	.6427**	.0928	.1536	.1574	.0044
DEP	.0762	.3818**	-.0093	.1207	.0666	-.0932
NA	.2933*	.6620**	.1024	.2470	.0723	-.0070
PA	.1670	.0507	.0471	.1796	-.0633	-.0400
LS	.1054	-.1665	-.2198	-.1544	-.0279	.0443
SSN	.0670	-.0463	-.1007	-.0403	.0798	-.0868
SSS	.0555	-.1201	-.0562	.0545	-.1638	.0480
OPT	.1214	-.0672	-.3386*	-.3185*	.1415	-.1326
MIL	.1342	-.0255	-.0675	.0334	-.0553	-.0256
LOC	-.2078	.3487*	.2840	.3314*	-.1933	.2323
HLOC	.1154	-.0420	.1311	.0889	-.0866	-.0652

Variables	HP	ANX	DEP	NA	PA	LS
ANX	.0678					
DEP	.0853	.7213**				
NA	-.1149	.7633**	.6048**			
PA	-.2316	-.0041	-.1430	.1894		
LS	-.6376**	-.2846	-.3978**	-.2373	.2103	
SSN	-.3258*	-.1112	-.1627	.0773	.4443**	.3046*
SSS	-.1337	-.0846	-.2145	-.0401	.3529*	.2928*
OPT	-.5610**	-.1907	-.4394**	-.0421	.2817	.6517**
MIL	-.3193*	-.0801	-.2288	-.0894	.3936**	.5587**
LOC	.3812**	.1782	.0747	-.0003	-.3862**	-.3936**
HlOC	.0863	.1361	.3860**	.0051	-.2986*	-.2179

Note. LE-Life events, HASS- Hassles, SYMFR-Symptom frequency, SYMIN-Symptom intensity, ADL-Disability, SHC-Self-rated health change, HP-Hopelessness, ANX-Anxiety, DEP-Depression, NA-Negative affect, PA-Positive affect, LS-Life satisfaction, SSN, Social support network, SSS-Social support satisfaction, OPT-Optimism, MIL-Meaning in life, LOC-Locus of control, HLOC-Health locus of control.

Table E-2. *Intercorrelations of all Longitudinal Variables (N=60)*

Variables	HASS	LE	HP	ANX	DEP	NA
LE	.1027					
HP	.0495	.3123*				
ANX	.1919	.2486	.2922*			
DEP	.1907	.0871	.2156	.7111**		
NA	.3058*	.2163	.2355	.7361**	.5857**	
PA	-.1249	-.1784	-.1972	-.3931**	-.4495**	-.3671**
LS	-.2546*	-.2297	-.2602*	-.4771**	-.4479**	-.4432**
DIS	-.1006	-.1323	-.0849	-.2787*	-.1226	-.2020
SHC	.0997	-.2509*	-.2237	-.2635*	-.0639	-.2248
SYMIN	.3645**	.1177	.0218	.1062	.0948	.0591
SYMFR	.1545	.0649	-.1711	.1539	.0647	.1358
FIM	-.0127	-.0404	-.0109	.1081	.0813	.0118
IMP	-.0697	.1991	-.1262	.2147	.0889	.1689
NDYS	.1700	-.0641	-.0387	.0507	.1903	-.0067
OHC	-.1625	-.3081*	-.0606	-.3457**	-.2079	-.2351
LOC	-.1495	.0189	.0554	-.0166	-.0196	.1327
HLOC	.0616	-.0356	-.0723	.0496	-.0123	-.0127
MIL	-.0479	.1029	.0092	-.0497	-.0693	-.0902
OPT	.1271	.1412	.0539	-.0244	.0682	-.1311
SSN	.1325	.1061	.0384	.0168	.0015	-.1900
SSS	-.0102	.0693	.1381	.0514	.0146	-.0044

Variables	PA	LS	DIS	SHC	SYMIN	SYMFR
LS	.4440**					
DIS	.2807*	.0204				
SHC	.1700	.0793	.1673			
SYMIN	-.2306	-.2057	-.2407	-.1515		
SYMFR	-.2434	-.0337	-.3737**	-.3050*	.6511**	
FIM	.0863	.0653	-.0795	-.0597	-.0194	.1024
IMP	.0582	-.0702	-.1452	.1191	-.1195	-.2345
NDYS	.0015	-.0589	.0807	-.0504	.1613	-.1074
OHC	.2197	.2871*	.0892	.6743**	-.1562	-.1944
LOC	.0225	-.0327	.2378	-.0066	-.1869	-.2335
HLOC	.0911	.0737	-.1026	-.0039	.0063	.1217
MIL	-.0098	.0013	.0856	.0068	.0632	.0418
OPT	.0921	-.0550	-.2682*	.0856	.0889	-.0305
SSN	.0257	-.0010	-.2296	.0631	.2186	.1433
SSS	-.0581	-.0351	-.0598	-.0142	.2049	.1220

(cont'd)

Table E-2. (cont'd)

Variables	FIM	IMP	NDYS	OHC	LOC	HLOC
IMP	-.1416					
NDYS	-.2437	.2503*				
OHC	.0336	-.0395	-.1719			
LOC	.0012	.1437	-.0188	.0000		
HLOC	.1846	-.0328	-.0114	.0000	-.3793**	
MIL	-.0870	-.1807	-.0405	.0000	-.1458	-.3219**
OPT	-.1105	.0385	.0232	.0000	-.3845**	-.2742*
SSN	-.1121	-.0823	-.0217	.0000	-.6726**	-.0143
SSS	-.0141	-.0409	-.0686	.0000	-.1172	-.2485

Variables	MIL	OPT	SSN
OPT	.1806		
SSN	.1801	.6619**	
SSS	.1126	.1012	.5536**

Note. HASS-Hassles, LE-Life events, HP-Hopelessness, ANX-Anxiety, DEP-Depression, NA-Negative affect, PA-Positive affect, LS-Life satisfaction, DIS-Disability (ADL), SHC-self-rated health change, SYMIN-Symptom intensity, SYMFR-Symptom frequency, FIM-Disability, IMP-Impairment status, NDYS-Neurologic dysfunction, OHC-Other-rated health change, LOC-Locus of control, HLOC-Health locus of control, MIL-Meaning in life, OPT-Optimism, SSN-Social Support network, SSS- Social support satisfaction.

APPENDIX F: CROSS-SECTIONAL REGRESSION SUMMARY TABLES PREDICTING PHYSICAL HEALTH STATUS

Table F-1. *Results for Self-rated Health Change Regressed on Well-being and Disposition (N = 45)*

Variable	Beta	*t*
Main Effects		
Hopelessness	-.242	-1.010
Anxiety	.163	.529
Depression	-.346	-1.181
Positive affect	-.030	-.143
Negative affect	.077	.274
Life satisfaction	.197	.706
Meaning in life	-.052	-.253
Locus of control	.143	.643
Health locus of control	-.141	-.656
Optimism	-.488	-1.649
(Adj. R^2 = -.08, F = .67)		
Interaction Effects		
Hopelessness x Meaning in life	-.789	-.377
Anxiety x Meaning in life	-1.344	-1.038
Depression x Meaning in life	2.604	1.943
Positive affect x Meaning in life	.734	2.070
Negative affect x Meaning in life	-.862	-1.137
Life satisfaction x Meaning in life	-1.532	-1.020
Hopelessness x Locus of control	-.681	-1.170
Anxiety x Locus of control	-.166	-.222
Depression x Locus of control	-.002	-.003
Positive affect x Locus of control	1.083	1.888
Negative affect x Locus of control	-.078	-.083
Life satisfaction x Locus of control	-.162	-.285
Hopelessness x Health locus of control	-.367	-.383
Anxiety x Health locus of control	-.386	-.769
Depression x Health locus of control	-.798	-1.299
Positive affect x Health locus of control	.191	.450
Negative affect x Health locus of control	.829	1.163
Life satisfaction x Health locus of control	-.460	-.448
Hopelessness x Optimism	.488	.337
Anxiety x Optimism	1.021	.890
Depression x Optimism	-1.216	-1.447
Positive affect x Optimism	-.334	-.576
Negative affect x Optimism	.534	.746
Life satisfaction x Optimism	3.080	2.010
(Adj. R^2 = .01, F = 1.02)		
(R^2 chg F = 1.14)		

Table F-2. *Results for Symptom Frequency Regressed on Well-being and Disposition (N = 45)*

Variable	Beta	*t*
Main Effects		
Hopelessness	-.138	-.616
Anxiety	.140	.481
Depression	-.496	-1.803
Positive affect	.140	.720
Negative affect	.222	.837
Life satisfaction	-.055	-.210
Meaning in life	.027	.141
Locus of control	.175	.836
Health locus of control	.123	.608
Optimism	-.471	-1.697
(Adj. R^2 = .05, F = 1.22)		
Interaction Effects		
Hopelessness x Meaning in life	-.058	-.022
Anxiety x Meaning in life	1.198	.745
Depression x Meaning in life	-1.612	-.969
Positive affect x Meaning in life	-.131	-.298
Negative affect x Meaning in life	-.010	-.011
Life satisfaction x Meaning in life	-.125	-.067
Hopelessness x Locus of control	-.832	-1.152
Anxiety x Locus of control	.117	.126
Depression x Locus of control	-.253	-.288
Positive affect x Locus of control	.339	.476
Negative affect x Locus of control	-.741	-.633
Life satisfaction x Locus of control	.186	.263
Hopelessness x Health locus of control	-.142	-.120
Anxiety x Health locus of control	-.165	-.265
Depression x Health locus of control	.431	.565
Positive affect x Health locus of control	.330	.627
Negative affect x Health locus of control	.080	.091
Life satisfaction x Health locus of control	.221	.173
Hopelessness x Optimism	-.550	-.306
Anxiety x Optimism	-1.583	-1.113
Depression x Optimism	.760	.728
Positive affect x Optimism	-.030	-.042
Negative affect x Optimism	.063	.071
Life satisfaction x Optimism	-.263	-.138
(Adj. R^2 = -.52, F = .56)		
(R^2 chg F = .47)		

Table F-3. *Results for Symptom Intensity Regressed on Well-being and Disposition (N = 45)*

Variable	Beta	*t*
Main Effects		
Hopelessness	-.059	-.282
Anxiety	-.210	-.781
Depression	-.111	-.434
Positive affect	.318	1.758
Negative affect	.429	1.744
Life satisfaction	.129	.531
Meaning in life	.081	.451
Locus of control	.431	2.224*
Health locus of control	.136	.727
Optimism	-.361	-1.401
(Adj. R^2 = .18, F = 1.97)		
Interaction Effects		
Hopelessness x Meaning in life	-.352	-.164
Anxiety x Meaning in life	.743	.560
Depression x Meaning in life	-1.026	-.747
Positive affect x Meaning in life	-.126	-.346
Negative affect x Meaning in life	.220	.284
Life satisfaction x Meaning in life	-.251	-.163
Hopelessness x Locus of control	-.837	-1.404
Anxiety x Locus of control	.280	.367
Depression x Locus of control	-.098	-.135
Positive affect x Locus of control	-.003	-.005
Negative affect x Locus of control	-.203	-.210
Life satisfaction x Locus of control	.292	.500
Hopelessness x Health locus of control	-.825	-.840
Anxiety x Health locus of control	.083	.161
Depression x Health locus of control	.036	.057
Positive affect x Health locus of control	-.007	-.017
Negative affect x Health locus of control	.231	.316
Life satisfaction x Health locus of control	-.298	-.283
Hopelessness x Optimism	-2.021	-1.360
Anxiety x Optimism	-1.186	-1.009
Depression x Optimism	.317	.367
Positive affect x Optimism	-.340	-.572
Negative affect x Optimism	.212	.288
Life satisfaction x Optimism	-1.229	-.782
(Adj. R^2 = -.04, F = .96)		
(R^2 chg F = .71)		

* $p < .05$

Table F-4. *Results for Disability (ADL) Regressed on Well-being and Disposition (N = 45)*

Variable	Beta	*t*
Main Effects		
Hopelessness	.007	.031
Anxiety	.441	1.435
Depression	-.093	-.319
Positive affect	-.218	-1.055
Negative affect	-.206	-.733
Life satisfaction	-.178	-.643
Meaning in life	-.033	-.161
Locus of control	-.391	-1.770
Health locus of control	-.185	-.865
Optimism	.098	.334
(Adj. R^2 = -.07, F = .72)		
Interaction Effects		
Hopelessness x Meaning in life	-2.619	-1.328
Anxiety x Meaning in life	-1.607	-1.319
Depression x Meaning in life	2.477	1.963
Positive affect x Meaning in life	.621	1.863
Negative affect x Meaning in life	-.411	-.576
Life satisfaction x Meaning in life	-1.956	-1.384
Hopelessness x Locus of control	.140	.255
Anxiety x Locus of control	.485	.692
Depression x Locus of control	-.191	-.287
Positive affect x Locus of control	-.157	-.290
Negative affect x Locus of control	.315	.354
Life satisfaction x Locus of control	-.956	-1.782
Hopelessness x Health locus of control	-1.036	-1.148
Anxiety x Health locus of control	.201	.425
Depression x Health locus of control	-.310	-.535
Positive affect x Health locus of control	-.760	-1.902
Negative affect x Health locus of control	.196	.292
Life satisfaction x Health locus of control	-.263	-.272
Hopelessness x Optimism	-.613	-.449
Anxiety x Optimism	3.102	2.875*
Depression x Optimism	-1.497	-1.892
Positive affect x Optimism	.553	1.013
Negative affect x Optimism	-1.238	-1.835
Life satisfaction x Optimism	-1.359	-.942
(Adj. R^2 = .13, F = 1.19)		
(R^2 chg F = 1.32)		

* $p < .05$

Table F-5. *Results for Self-rated Health Change Regressed on Well-being and Social Support (N = 45)*

Variable	Beta	*t*
Main Effects		
Hopelessness	-.123	-.521
Anxiety	.125	.411
Depression	-.228	-.889
Positive affect	-.064	-.331
Negative affect	.038	.133
Life satisfaction	-.049	-.197
Social support network	-.158	-.774
Social support satisfaction	.105	.543
(Adj. R^2 = -.16, F = .22)		
Interaction Effects		
Hopelessness x Social support network	.242	.672
Anxiety x Social support network	-.385	-.640
Depression x Social support network	-.491	-1.222
Positive affect x Social support network	-.450	-1.556
Negative affect x Social support network	.699	1.131
Life satisfaction x Social support network	.179	.458
Hopelessness x Social support satisfaction	.042	.151
Anxiety x Social support satisfaction	1.023	1.541
Depression x Social support satisfaction	-.335	-.765
Positive affect x Social support satisfaction	-.045	-.121
Negative affect x Social support satisfaction	-.651	-1.243
Life satisfaction x Social support satisfaction	-.057	-.169
(Adj. R^2 = -.23, F = .59)		
(R^2 chg F = .84)		

Table F-6. *Results for Symptom Frequency Regressed on Well-being and Social Support (N = 45)*

Variable	Beta	*t*
Main Effects		
Hopelessness	-.020	-.086
Anxiety	.135	.454
Depression	-.268	-1.071
Positive affect	.091	.483
Negative affect	.086	.306
Life satisfaction	-.267	-1.096
Social support network	-.097	-.485
Social support satisfaction	-.011	-.057
(Adj. R^2 = -.11, F = .47)		
Interaction Effects		
Hopelessness x Social support network	-.454	-1.335
Anxiety x Social support network	.580	1.023
Depression x Social support network	-.204	-.539
Positive affect x Social support network	.093	.339
Negative affect x Social support network	-.676	-1.159
Life satisfaction x Social support network	-.685	-1.862
Hopelessness x Social support satisfaction	-.182	-.698
Anxiety x Social support satisfaction	-1.036	-1.655
Depression x Social support satisfaction	.606	1.469
Positive affect x Social support satisfaction	.327	.928
Negative affect x Social support satisfaction	.795	1.610
Life satisfaction x Social support satisfaction	-.052	-.164
(Adj. R^2 = -.10, F = .81)		
(R^2 chg F = 1.03)		

Table F-7. *Results for Symptom Intensity Regressed on Well-being and Social Support (N = 45)*

Variable	Beta	*t*
Main Effects		
Hopelessness	.040	.176
Anxiety	-.111	-.379
Depression	8.364	.003
Positive affect	.193	1.036
Negative affect	.289	1.045
Life satisfaction	-.113	-.472
Social support network	-.160	-.816
Social support satisfaction	.101	.545
(Adj. R^2 = -.07, F = .62)		
Interaction Effects		
Hopelessness x Social support network	-.615	-1.771
Anxiety x Social support network	.253	.436
Depression x Social support network	.016	.042
Positive affect x Social support network	.043	.155
Negative affect x Social support network	-.594	-.997
Life satisfaction x Social support network	-.644	-1.714
Hopelessness x Social support satisfaction	.096	.360
Anxiety x Social support satisfaction	-.534	-.835
Depression x Social support satisfaction	.202	.480
Positive affect x Social support satisfaction	.326	.905
Negative affect x Social support satisfaction	.696	1.380
Life satisfaction x Social support satisfaction	.121	.375
(Adj. R^2 = -.14, F = .73)		
(R^2 chg F = .82)		

Table F-8. *Results for Disability (ADL) Regressed on Well-being and Social Support (N = 45)*

Variable	Beta	*t*
Main Effects		
Hopelessness	.022	.098
Anxiety	.375	1.275
Depression	-.139	-.561
Positive affect	-.080	-.425
Negative affect	-.140	-.503
Life satisfaction	.017	.070
Social support network	.271	1.371
Social support satisfaction	-.267	-1.425
(Adj. R^2 = -.09, F = .55)		
Interaction Effects		
Hopelessness x Social support network	.366	1.013
Anxiety x Social support network	-.695	-1.155
Depression x Social support network	.114	.282
Positive affect x Social support network	-.183	-.631
Negative affect x Social support network	.660	1.065
Life satisfaction x Social support network	.355	.909
Hopelessness x Social support satisfaction	-.517	-1.871
Anxiety x Social support satisfaction	.677	1.018
Depression x Social support satisfaction	.134	.306
Positive affect x Social support satisfaction	.357	.954
Negative affect x Social support satisfaction	-1.064	-2.029
Life satisfaction x Social support satisfaction	-.395	-1.174
(Adj. R^2 = -.23, F = .58)		
(R^2 chg F = .64)		

APPENDIX G: WITHIN-SUBJECT REGRESSION SUMMARY TABLES PREDICTING PSYCHOLOGICAL WELL-BEING

Table G-1. *Results for Anxiety Regressed on Stressors, Disposition, Social Support, Health Status and Time (N = 60)*

Variable	Beta	*t*
Main Effects		
Hassles	.197	1.257
Life events	.100	.654
Meaning in life	.020	.133
Locus of control	.009	.036
Health locus of control	-.025	-.127
Optimism	-.150	-.607
Social support network	.063	.177
Social support satisfaction	.023	.103
Self-rated health change	-.067	-.309
Disability (ADL)	-.205	-1.274
Symptom frequency	.055	.268
Symptom intensity	-.079	-.398
Other-rated health change	-.239	-1.107
Impairment status	.199	1.203
Disability (FIM)	.107	.729
Neurologic dysfunction	-.037	-.207
Time	.077	.431
(Adj. R^2 = -.02, F = .95)		
Interaction Effects		
Hassles x Meaning in life	.320	1.920
Life events x Meaning in life	-.115	-.619
Hassles x Locus of control	-.139	-.259
Life events x Locus of control	.247	.583
Hassles x Health locus of control	.016	.052
Life events x Health locus of control	-.186	-.597
Hassles x Optimism	-.302	-.693
Life events x Optimism	-.136	-.456
Hassles x Social support network	.424	.527
Life events x Social support network	.089	.190
Hassles x Social support satisfaction	-.226	-.607
Life events x Social support satisfaction	.055	.177
(Adj. R^2 = .04, F = 1.08)		
(R^2 chg F = 1.19)		

Table G-2. *Results for Depression Regressed on Stressors, Disposition, Social Support, Health Status and Time (N = 60)*

Variable	Beta	*t*
Main Effects		
Hassles	.110	.642
Life events	.057	.344
Meaning in life	-.071	-.428
Locus of control	-.105	-.408
Health locus of control	-.045	-.212
Optimism	.144	.532
Social support network	-.263	-.682
Social support satisfaction	.140	.575
Self-rated health change	.160	.676
Disability (ADL)	-.091	-.519
Symptom frequency	.063	.282
Symptom intensity	-.052	-.240
Other-rated health change	-.254	-1.080
Impairment status	-.007	-.037
Disability (FIM)	.115	.720
Neurologic dysfunction	.165	.835
Time	.050	.255
(Adj. R^2 = -.21, F = .40)		
Interaction Effects		
Hassles x Meaning in life	.430	2.264*
Life events x Meaning in life	-.212	-1.004
Hassles x Locus of control	-.097	-.159
Life events x Locus of control	-.315	-.654
Hassles x Health locus of control	.196	.559
Life events x Health locus of control	-.304	-.858
Hassles x Optimism	-.164	-.331
Life events x Optimism	-.246	-.724
Hassles x Social support network	.065	.071
Life events x Social support network	-.131	-.247
Hassles x Social support satisfaction	-.146	-.345
Life events x Social support satisfaction	.226	.636
(Adj. R^2 = -.25, F = .60)		
(R^2 chg F = .89)		

* $p < .05$

Table G-3. *Results for Negative Affect Regressed on Stressors, Disposition, Social Support, Health Status and Time (N = 60)*

Variable	Beta	*t*
Main Effects		
Hassles	.440	2.945**
Life events	.115	.790
Meaning in life	-.014	-.098
Locus of control	-.086	-.384
Health locus of control	-.024	-.126
Optimism	.033	.140
Social support network	-.473	-1.407
Social support satisfaction	.242	1.144
Self-rated health change	-.169	-.820
Disability (ADL)	-.148	-.965
Symptom frequency	.136	.697
Symptom intensity	-.189	-1.002
Other-rated health	-.047	-.230
Impairment status	.154	.978
Disability (FIM)	-.080	-.575
Neurologic dysfunction	-.148	-.861
Time	.130	.768
(Adj. R^2 = .08, F = 1.30)		
Interaction Effects		
Hassles x Meaning in life	.228	1.480
Life events x Meaning in life	-.270	-1.576
Hassles x Locus of control	.287	.575
Life events x Locus of control	-.375	-.956
Hassles x Health locus of control	.286	1.006
Life events x Health locus of control	-.537	-1.864
Hassles x Optimism	-.177	-.439
Life events x Optimism	.117	.424
Hassles x Social support network	.730	.980
Life events x Social support network	-.474	-1.097
Hassles x Social support satisfaction	-.455	-1.319
Life events x Social support satisfaction	.300	1.038
(Adj. R^2 = .18, F = 1.43)		
(R^2 chg F = 1.41)		

** $p < .01$

Table G-4. *Results for Positive Affect Regressed on Stressors, Disposition, Social Support, Health Status and Time (N = 60)*

Variable	Beta	*t*
Main Effects		
Hassles	.009	.055
Life events	-.145	-.962
Meaning in life	.053	.350
Locus of control	.196	.841
Health locus of control	.300	1.547
Optimism	.337	1.380
Social support network	.044	.126
Social support satisfaction	.020	.090
Self-rated health change	-.027	-.129
Disability (ADL)	.339	2.136*
Symptom frequency	.007	.033
Symptom intensity	-.098	-.501
Other-rated health change	.077	.363
Impairment status	.090	.552
Disability (FIM)	.058	.400
Neurologic dysfunction	-.131	-.738
Time	.260	1.482
(Adj. R^2 = .01, F = 1.05)		
Interaction Effects		
Hassles x Meaning in life	-.454	-3.014**
Life events x Meaning in life	.486	2.903**
Hassles x Locus of control	.063	.130
Life events x Locus of control	.600	1.566
Hassles x Health locus of control	-.170	-.612
Life events x Health locus of control	.548	1.947
Hassles x Optimism	.112	.284
Life events x Optimism	.298	1.107
Hassles x Social support network	.088	.121
Life events x Social support network	.081	.193
Hassles x Social support satisfaction	.039	.116
Life events x Social support satisfaction	-.131	-.465
(Adj. R^2 = .21, F = 1.56)		
(R^2 chg F = 1.90)		

* $p < .05$, ** $p < .01$

APPENDIX H: WITHIN-SUBJECT REGRESSION SUMMARY TABLES PREDICTING PHYSICAL HEALTH STATUS

Table H-1. *Results for Symptom Frequency Regressed on Well-being, Disposition, and Time (N = 60)*

Variable	Beta	*t*
Main Effects		
Hopelessness	-.229	-1.668
Anxiety	.185	.809
Depression	-.153	-.773
Positive affect	-.251	-1.521
Negative affect	.122	.607
Life satisfaction	.099	.611
Meaning in life	.031	.218
Locus of control	-.236	-1.310
Health locus of control	.018	.102
Optimism	-.050	-.295
Time	-.085	-.610
(Adj. R^2 = .02, F = 1.12)		
Interaction Effects		
Hopelessness x Meaning in life	.065	.177
Anxiety x Meaning in life	.099	.345
Depression x Meaning in life	.040	.123
Positive affect x Meaning in life	-.235	-.806
Negative affect x Meaning in life	.008	.025
Life satisfaction x Meaning in life	.096	.273
Hopelessness x Locus of control	.508	.813
Anxiety x Locus of control	-1.020	-1.378
Depression x Locus of control	.725	1.498
Positive affect x Locus of control	-.421	-.992
Negative affect x Locus of control	1.347	1.309
Life satisfaction x Locus of control	1.267	1.917
Hopelessness x Health Locus of control	.464	1.036
Anxiety x Health locus of control	-.929	-1.712
Depression x Health locus of control	.635	1.080
Positive affect x Health locus of control	-.345	-1.030
Negative affect x Health locus of control	.607	1.000
Life satisfaction x Health locus of control	.640	1.668
Hopelessness x Optimism	.044	.137
Anxiety x Optimism	-.577	-.999
Depression x Optimism	.605	1.379
Positive affect x Optimism	-.541	-1.531
Negative affect x Optimism	.808	1.050
Life satisfaction x Optimism	.766	1.639
(Adj. R^2 = .05, F = 1.09)		
(R^2 chg F = 1.06)		

Table H-2. *Results for Symptom Intensity Regressed on Well-being, Disposition, and Time (N = 60)*

Variable	Beta	*t*
Main Effects		
Hopelessness	-.041	-.285
Anxiety	.034	.141
Depression	-.075	-.359
Positive affect	-.204	-1.170
Negative affect	-.035	-.165
Life satisfaction	-.172	-1.003
Meaning in life	.017	.108
Locus of control	-.180	-.949
Health locus of control	-.025	-.134
Optimism	.023	.126
Time	.047	.321
(Adj. R^2 = -.09, F = .54)		
Interaction Effects		
Hopelessness x Meaning in life	-.503	-1.413
Anxiety x Meaning in life	.596	2.136*
Depression x Meaning in life	-.014	-.045
Positive affect x Meaning in life	-.038	-.135
Negative affect x Meaning in life	-.362	-1.227
Life satisfaction x Meaning in life	-.077	-.226
Hopelessness x Locus of control	-.613	-1.008
Anxiety x Locus of control	.364	.506
Depression x Locus of control	.614	1.304
Positive affect x Locus of control	-.047	-.114
Negative affect x Locus of control	-.565	-.565
Life satisfaction x Locus of control	.822	1.279
Hopelessness x Health Locus of control	-.368	-.844
Anxiety x Health Locus of control	-.365	-.693
Depression x Health Locus of control	1.120	1.961
Positive affect x Health locus of control	-.176	-.541
Negative affect x Health locus of control	-.252	-.427
Life satisfaction x Health locus of control	.508	1.361
Hopelessness x Optimism	-.428	-1.365
Anxiety x Optimism	.282	.502
Depression x Optimism	.484	1.135
Positive affect x Optimism	.133	.388
Negative affect x Optimism	-.123	-.165
Life satisfaction x Optimism	.468	1.031
(Adj. R^2 = .10, F = 1.19)		
(R^2 chg F = 1.43)		

* $p < .05$

Table H-3. *Results for Other-rated Health Change Regressed on Well-being, Disposition, and Time (N = 60)*

Variable	Beta	*t*
Main Effects		
Hopelessness	.068	.486
Anxiety	-.413	-1.779
Depression	.100	.497
Positive affect	.039	.233
Negative affect	.066	.327
Life satisfaction	.127	.771
Meaning in life	-.009	-.059
Locus of control	-.022	-.119
Health locus of control	-6.461	-.004
Optimism	-.015	-.089
Time	.167	1.177
(Adj. R^2 = -.01, F = .96)		
Interaction Effects		
Hopelessness x Meaning in life	-.122	-.307
Anxiety x Meaning in life	-.288	-.923
Depression x Meaning in life	.403	1.128
Positive affect x Meaning in life	.213	.671
Negative affect x Meaning in life	.224	.677
Life satisfaction x Meaning in life	.048	.126
Hopelessness x Locus of control	.191	.281
Anxiety x Locus of control	-.143	-.177
Depression x Locus of control	-.238	-.452
Positive affect x Locus of control	.109	.236
Negative affect x Locus of control	.792	.707
Life satisfaction x Locus of control	.325	.451
Hopelessness x Health locus of control	.190	.388
Anxiety x Health locus of control	-.146	-.247
Depression x Health locus of control	-.015	-.023
Positive affect x Health locus of control	.557	1.529
Negative affect x Health locus of control	.617	.934
Life satisfaction x Health locus of control	.084	.201
Hopelessness x Optimism	.083	.236
Anxiety x Optimism	.207	.329
Depression x Optimism	-.492	-1.032
Positive affect x Optimism	-.040	-.103
Negative affect x Optimism	.619	.739
Life satisfaction x Optimism	.323	.636
(Adj. R^2 = -.13, F = .81)		
(R^2 chg F = .79)		

Table H-4. *Results for Disability (FIM) Regressed on Well-being, Disposition and Time (N = 60)*

Variable	Beta	*t*
Main Effects		
Hopelessness	-.006	-.039
Anxiety	.215	.875
Depression	.117	.550
Positive affect	.123	.693
Negative affect	-.146	-.678
Life satisfaction	.087	.502
Meaning in life	-.010	-.062
Locus of control	.055	.285
Health locus of control	.153	.795
Optimism	-.074	-.405
Time	-.005	-.033
(Adj. R^2 = -.13, F = .40)		
Interaction Effects		
Hopelessness x Meaning in life	-.675	-1.388
Anxiety x Meaning in life	.072	.189
Depression x Meaning in life	-.231	-.530
Positive affect x Meaning in life	.024	.063
Negative affect x Meaning in life	-.004	-.010
Life satisfaction x Meaning in life	-.218	-.464
Hopelessness x Locus of control	-.850	-1.023
Anxiety x Locus of control	-.016	-.017
Depression x Locus of control	-.107	-.166
Positive affect x Locus of control	.467	.828
Negative affect x Locus of control	-.057	-.041
Life satisfaction x Locus of control	.364	.414
Hopelessness x Health locus of control	-.677	-1.135
Anxiety x Health locus of control	-.273	-.379
Depression x Health locus of control	-.394	-.505
Positive affect x Health locus of control	-.158	-.356
Negative affect x Health locus of control	.269	.333
Life satisfaction x Health locus of control	-.114	-.223
Hopelessness x Optimism	.230	.537
Anxiety x Optimism	.669	.871
Depression x Optimism	-.146	-.251
Positive affect x Optimism	.213	.455
Negative affect x Optimism	-.544	-.532
Life satisfaction x Optimism	.167	.269
(Adj. R^2 = -.68, F = .32)		
(R^2 chg F = .34)		

Table H-5. *Results for Neurologic Dysfunction Regressed on Well-being, Disposition and Time (N = 60)*

Variable	Beta	*t*
Main Effects		
Hopelessness	-.074	-.569
Anxiety	-.097	-.445
Depression	.241	1.286
Positive affect	-.062	-.393
Negative affect	-.156	-.823
Life satisfaction	-.167	-1.089
Meaning in life	-.048	-.350
Locus of control	-.017	-.098
Health locus of control	-.020	-.117
Optimism	-.019	-.117
Time	.498	3.754**
(Adj. R^2 = .12, F = 1.73)		
Interaction Effects		
Hopelessness x Meaning in life	.534	1.475
Anxiety x Meaning in life	.440	1.551
Depression x Meaning in life	-.155	-.478
Positive affect x Meaning in life	-.170	-.587
Negative affect x Meaning in life	-.190	-.631
Life satisfaction x Meaning in life	-.015	-.043
Hopelessness x Locus of control	.156	.252
Anxiety x Locus of control	.278	.379
Depression x Locus of control	-.480	-1.003
Positive affect x Locus of control	-.455	-1.083
Negative affect x Locus of control	-.211	-.207
Life satisfaction x Locus of control	-1.002	-1.532
Hopelessness x Health locus of control	.200	.451
Anxiety x Health locus of control	.861	1.603
Depression x Health locus of control	-.096	-.165
Positive affect x Health locus of control	-.386	-1.167
Negative affect x Health locus of control	-.943	-1.571
Life satisfaction x Health locus of control	-.225	-.593
Hopelessness x Optimism	-.566	-1.772
Anxiety x Optimism	-.038	-.067
Depression x Optimism	-.258	-.594
Positive affect x Optimism	-.391	-1.120
Negative affect x Optimism	-.043	-.057
Life satisfaction x Optimism	-.881	-1.906
(Adj. R^2 = .07, F = 1.12)		
(R^2 chg F = .89)		

** $p < .01$

Table H-6. *Results for Symptom Frequency Regressed on Well-being, Social Support and Time (N = 60)*

Variable	Beta	*t*
Main Effects		
Hopelessness	-.261	-1.915
Anxiety	.194	.853
Depression	-.160	-.828
Positive affect	-.273	-1.734
Negative affect	.128	.629
Life satisfaction	.118	.739
Social support network	.151	.929
Social support satisfaction	.056	.355
Time	-.084	-.605
(Adj. R^2 = .04, F = 1.25)		
Interaction Effects		
Hopelessness x Social support network	-.135	-.543
Anxiety x Social support network	-.126	-.299
Depression x Social support network	.191	.827
Positive affect x Social support network	-.081	-.328
Negative affect x Social support network	.028	.070
Life satisfaction x Social support network	-.093	-.360
Hopelessness x Social support satisfaction	.047	.274
Anxiety x Social support satisfaction	.152	.432
Depression x Social support satisfaction	-.319	-1.161
Positive affect x Social support satisfaction	.521	2.450*
Negative affect x Social support satisfaction	-.049	-.183
Life satisfaction x Social support satisfaction	-.477	-1.577
(Adj. R^2 = .12, F = 1.39)		
(R^2 chg F = 1.40)		

* $p < .05$

Table H-7. *Results for Symptom Intensity Regressed on Well-being, Social Support and Time (N = 60)*

Variable	Beta	*t*
Main Effects		
Hopelessness	-.070	-.494
Anxiety	.010	.044
Depression	-.062	-.312
Positive affect	-.211	-1.300
Negative affect	-.014	-.069
Life satisfaction	-.166	-1.008
Social support network	.166	.988
Social support satisfaction	.105	.649
Time	.048	.334
(Adj. R^2 = -.03, F = .84)		
Interaction Effects		
Hopelessness x Social support network	-.426	-1.670
Anxiety x Social support network	-.469	-1.085
Depression x Social support network	.257	1.083
Positive affect x Social support network	-.084	-.331
Negative affect x Social support network	.477	1.180
Life satisfaction x Social support network	-.323	-1.216
Hopelessness x Social support satisfaction	.370	2.111*
Anxiety x Social support satisfaction	.424	1.172
Depression x Social support satisfaction	-.727	-2.577*
Positive affect x Social support satisfaction	.041	.187
Negative affect x Social support satisfaction	-.339	-1.240
Life satisfaction x Social support satisfaction	-.102	-.327
(Adj. R^2 = .07, F = 1.22)		
(R^2 chg F = 1.44)		

* $p < .05$

Table H-8. *Results for Other-rated Health Regressed on Well-being, Social Support and Time (N = 60)*

Variable	Beta	*t*
Main Effects		
Hopelessness	.063	.462
Anxiety	-.413	-1.808
Depression	.098	.507
Positive affect	.036	.229
Negative affect	.071	.346
Life satisfaction	.130	.812
Social support network	.010	.062
Social support satisfaction	.012	.079
Time	.167	1.207
(Adj. R^2 = .03, F = 1.23)		
Interaction Effects		
Hopelessness x Social support network	.005	.018
Anxiety x Social support network	.744	1.705
Depression x Social support network	-.549	-2.289*
Positive affect x Social support network	.058	.227
Negative affect x Social support network	-.313	-.767
Life satisfaction x Social support network	.291	1.086
Hopelessness x Social support satisfaction	-.151	-.854
Anxiety x Social support satisfaction	-.746	-2.042*
Depression x Social support satisfaction	.582	2.044*
Positive affect x Social support satisfaction	-.155	-.704
Negative affect x Social support satisfaction	-.045	-.164
Life satisfaction x Social support satisfaction	-.313	-.996
(Adj. R^2 = .05, F = 1.16)		
(R^2 chg F = 1.09)		

* $p < .05$

Table H-9. *Results for Disability (ADL) Regressed on Well-being, Social Support and Time (N = 60)*

Variable	Beta	*t*
Main Effects		
Hopelessness	-.012	-.094
Anxiety	-.312	-1.426
Depression	.235	1.268
Positive affect	.329	2.177*
Negative affect	-.156	-.800
Life satisfaction	-.234	-1.533
Social support network	-.350	-2.249*
Social support satisfaction	.159	1.056
Time	-.010	-.073
(Adj. R^2 = .11, F =1.84)		
Interaction Effects		
Hopelessness x Social support network	-.342	-1.283
Anxiety x Social support network	.236	.523
Depression x Social support network	-.080	-.324
Positive affect x Social support network	-.245	-.919
Negative affect x Social support network	-.053	-.125
Life satisfaction x Social support network	-.293	-1.056
Hopelessness x Social support satisfaction	.200	1.095
Anxiety x Social support satisfaction	-.158	-.419
Depression x Social support satisfaction	.112	.380
Positive affect x Social support satisfaction	.217	.950
Negative affect x Social support satisfaction	-.192	-.671
Life satisfaction x Social support satisfaction	.162	.497
(Adj. R^2 = -.01, F =.97)		
(R^2 chg F = .48)		

* $p <$ .05

Table H-10. *Results for Disability (FIM) Regressed on Well-being, Social Support and Time (N = 60)*

Variable	Beta	*t*
Main Effects		
Hopelessness	-.023	-.160
Anxiety	.290	1.200
Depression	.106	.515
Positive affect	.140	.836
Negative affect	-.204	-.942
Life satisfaction	.099	.585
Social support network	-.215	-1.247
Social support satisfaction	.102	.615
Time	-.014	-.093
(Adj. R^2 = -.09, F = .47)		
Interaction Effects		
Hopelessness x Social support network	.192	.652
Anxiety x Social support network	1.056	2.122*
Depression x Social support network	-.008	-.030
Positive affect x Social support network	-.060	-.203
Negative affect x Social support network	-.937	-2.013
Life satisfaction x Social support network	.161	.526
Hopelessness x Social support satisfaction	-.055	-.273
Anxiety x Social support satisfaction	-.381	-.914
Depression x Social support satisfaction	-.047	-.145
Positive affect x Social support satisfaction	.101	.400
Negative affect x Social support satisfaction	.168	.533
Life satisfaction x Social support satisfaction	-.265	-.738
(Adj. R^2 = -.23, F = .47)		
(R^2 chg F = .51)		

* $p <$ .05

APPENDIX I: RAW AND Z-SCORES FOR INDIVIDUAL CASES

Table I-1. *Individual Raw and Z-scores (in bold) for Stressor Variables, Case by Time*

Hassles	T1	T2	T3	T4	T5	T6	T7
C1	9.00	2.00	8.00	5.00	2.00	7.00	6.00
	1.24	**-1.29**	**.88**	**-.21**	**-1.29**	**.52**	**.16**
C2	16.00	25.00	24.00	22.00	25.00	6.00	11.00
	-.32	**.87**	**.73**	**.47**	**.87**	**-1.64**	**-.98**
C3	21.00	13.00	14.00	10.00	4.00	7.00	3.00
	1.70	**.43**	**.59**	**-.05**	**-1.00**	**-.52**	**-1.15**
C4	14.00	4.00	16.00	11.00	3.00	3.00	1.00
	1.08	**-.56**	**1.41**	**.59**	**-.73**	**-.73**	**-1.06**
C5	26.00	19.00	13.00	32.00	5.00	3.00	5.00
	.99	**.38**	**-.15**	**1.52**	**-.86**	**-1.03**	**-.86**
C6	61.00	41.00	48.00	50.00	39.00	46.00	40.00
	1.90	**-.71**	**.20**	**.47**	**-.97**	**-.06**	**-.84**
C7	8.00	25.00	8.00	18.00	16.00	29.00	31.00
	-1.20	**.61**	**-1.20**	**-.14**	**-.35**	**1.03**	**1.24**
C8	14.00	11.00	17.00	9.00	4.00	20.00	5.00
	.43	**-.07**	**.93**	**-.41**	**-1.24**	**1.44**	**-1.08**
C9	.00	4.00	2.00	1.00	.00	.00	1.00
	-.78	**1.95**	**.59**	**-.10**	**-.78**	**-.78**	**-.10**
C10	32.00	33.00	38.00	34.00	33.00	19.00	49.00
	-.23	**-.11**	**.45**	**.00**	**-.11**	**-1.69**	**1.69**
C11	26.00	11.00	10.00	30.00	58.00	26.00	27.00
	-.05	**-1.00**	**-1.06**	**.20**	**1.96**	**-.05**	**.01**
C12	13.00	7.00	6.00	13.00	6.00	4.00	6.00
	1.42	**-.24**	**-.51**	**1.42**	**-.51**	**-1.06**	**1.51**
Life events							
C1	3.00	1.00	2.00	1.00	.00	.00	.00
	1.73	**.00**	**.87**	**.00**	**-.87**	**-.87**	**-.87**
C2	2.00	1.00	.00	1.00	1.00	.00	.00
	1.70	**.38**	**-.94**	**.38**	**.38**	**-.94**	**-.94**
C3	.00	.00	.00	1.00	.00	.00	2.00
	-.54	**-.54**	**-.54**	**.73**	**-.54**	**-.54**	**2.00**
C4	3.00	3.00	3.00	3.00	2.00	2.00	1.00
	.73	**.73**	**.73**	**.73**	**-.54**	**-.54**	**-1.82**
C5	2.00	1.00	2.00	2.00	.00	3.00	2.00
	.30	**-.75**	**.30**	**.30**	**-1.80**	**1.35**	**.30**
C6	3.00	3.00	.00	2.00	.00	3.00	4.00
	.54	**.54**	**-1.36**	**-.09**	**-1.36**	**.54**	**1.18**
C7	.00	6.00	.00	3.00	.00	.00	.00
	-.54	**2.00**	**-.54**	**.73**	**-.54**	**-.54**	**-.54**
C8	.00	.00	.00	3.00	3.00	.00	.00
	-.59	**-.59**	**-.59**	**1.46**	**1.46**	**-.59**	**-.59**
C9	.00	.00	.00	2.00	.00	2.00	.00
	-.59	**-.59**	**-.59**	**1.46**	**-.59**	**1.46**	**-.59**
C10	2.00	1.00	3.00	7.00	4.00	.00	2.00
	-.31	**-.75**	**.12**	**1.87**	**.56**	**-1.19**	**-.31**
C11	3.00	.00	5.00	2.00	5.00	4.00	3.00
	-.08	**-1.77**	**1.05**	**-.64**	**1.05**	**.48**	**-.08**
C12	.00	.00	.00	8.00	3.00	4.00	.00
	-.70	**-.70**	**-.70**	**1.90**	**.28**	**.60**	**-.70**

Table I-2. *Individual Raw and Z-scores (in bold) for Negative Well-being Variables, Case by Time*

Hopelessness	T1	T2	T3	T4	T5	T6	T7
C1	8.00	9.00	8.00	9.00	9.00	9.00	9.00
	-1.46	**.59**	**-1.46**	**.59**	**.59**	**.59**	**.59**
C2	8.00	9.00	8.00	10.00	10.00	10.00	9.00
	-1.27	**-.16**	**-1.27**	**.95**	**.95**	**.95**	**-.16**
C3	9.00	8.00	10.00	8.00	8.00	9.00	9.00
	.38	**-.94**	**1.70**	**-.94**	**-.94**	**.38**	**.38**
C4	8.00	9.00	8.00	8.00	8.00	8.00	8.00
	-.38	**2.27**	**-.38**	**-.38**	**-.38**	**-.38**	**-.38**
C5	10.00	8.00	8.00	8.00	8.00	8.00	8.00
	2.27	**-.38**	**-.38**	**-.38**	**-.38**	**-.38**	**-.38**
C6	10.00	10.00	9.00	9.00	8.00	10.00	14.00
	.00	**.00**	**-.52**	**-.52**	**-1.04**	**.00**	**2.09**
C7	12.00	9.00	9.00	8.00	9.00	10.00	10.00
	1.91	**-.45**	**-.45**	**-1.23**	**-.45**	**.34**	**.34**
C8	9.00	9.00	11.00	10.00	9.00	9.00	8.00
	-.30	**-.30**	**1.80**	**.75**	**-.30**	**-.30**	**-1.35**
C9	9.00	8.00	9.00	9.00	9.00	9.00	9.00
	.38	**-2.27**	**.38**	**.38**	**.38**	**.38**	**.38**
C10	9.00	9.00	9.00	8.00	8.00	8.00	8.00
	1.07	**1.07**	**1.07**	**-.80**	**-.80**	**-.80**	**-.80**
C11	9.00	8.00	9.00	8.00	8.00	8.00	8.00
	1.46	**-.59**	**1.46**	**-.59**	**-.59**	**-.59**	**-.59**
C12	8.00	8.00	10.00	12.00	8.00	8.00	8.00
	-.54	**-.54**	**.73**	**2.00**	**-.54**	**-.54**	**-.54**
Depression							
C1	10.00	6.00	13.00	11.00	8.00	10.00	8.00
	.25	**-1.49**	**1.55**	**.68**	**-.62**	**.25**	**-.62**
C2	11.00	11.00	10.00	11.00	14.00	13.00	11.00
	-.41	**-.41**	**-1.12**	**-.41**	**1.74**	**1.02**	**-.41**
C3	10.00	5.00	8.00	6.00	7.00	6.00	6.00
	1.88	**-1.11**	**.68**	**-.51**	**.09**	**-.51**	**-.51**
C4	10.00	9.00	6.00	4.00	9.00	8.00	9.00
	1.01	**.54**	**-.88**	**-1.82**	**.54**	**.07**	**.54**
C5	15.00	9.00	12.00	13.00	4.00	6.00	9.00
	1.35	**-.18**	**.59**	**.84**	**-1.46**	**-.95**	**-.18**
C6	11.00	11.00	8.00	8.00	9.00	14.00	12.00
	.26	**.26**	**-1.09**	**-1.09**	**-.64**	**1.60**	**.71**
C7	14.00	10.00	9.00	10.00	14.00	10.00	12.00
	1.32	**-.62**	**-1.11**	**-.62**	**1.32**	**-.62**	**.35**
C8	4.00	9.00	10.00	13.00	4.00	5.00	11.00
	-1.10	**.27**	**.55**	**1.37**	**-1.10**	**-.82**	**.82**
C9	9.00	8.00	6.00	9.00	9.00	9.00	10.00
	.34	**-.45**	**-2.02**	**.34**	**.34**	**.34**	**1.12**
C10	12.00	8.00	12.00	7.00	8.00	7.00	11.00
	1.19	**-.56**	**1.19**	**-1.00**	**-.56**	**-1.00**	**.75**
C11	15.00	11.00	12.00	9.00	13.00	10.00	16.00
	1.06	**-.50**	**-.11**	**-1.28**	**.28**	**-.89**	**1.45**
C12	7.00	10.00	7.00	7.00	12.00	4.00	5.00
	-.16	**.93**	**-.16**	**-.16**	**1.66**	**-1.24**	**-.88**

Table I-2 (cont'd). *Individual Raw and Z-scores (in bold) for Negative Well-being variables, Case by Time*

Anxiety	T1	T2	T3	T4	T5	T6	T7
C1	26.00	15.00	26.00	18.00	16.00	22.00	18.00
	1.28	**-1.13**	**1.28**	**-.47**	**-.91**	**.41**	**-.47**
C2	24.00	21.00	23.00	24.00	28.00	26.00	24.00
	-.13	**-1.48**	**-.58**	**-.13**	**1.68**	**.77**	**-.13**
C3	19.00	13.00	15.00	10.00	10.00	9.00	15.00
	1.66	**.00**	**.55**	**-.83**	**-.83**	**-1.11**	**.55**
C4	19.00	18.00	10.00	13.00	18.00	17.00	18.00
	.86	**.56**	**-1.84**	**-.94**	**.56**	**.26**	**.56**
C5	26.00	23.00	26.00	27.00	12.00	23.00	16.00
	.73	**.20**	**.73**	**.90**	**-1.73**	**.20**	**-1.03**
C6	32.00	24.00	18.00	23.00	21.00	34.00	28.00
	1.07	**-.29**	**-1.32**	**-.46**	**-.81**	**1.42**	**.39**
C7	19.00	22.00	20.00	16.00	23.00	15.00	20.00
	-.10	**.93**	**.24**	**-1.12**	**1.27**	**-1.46**	**.24**
C8	17.00	19.00	13.00	22.00	13.00	10.00	17.00
	.28	**.77**	**-.70**	**1.50**	**-.70**	**-1.43**	**.28**
C9	10.00	12.00	9.00	14.00	12.00	12.00	14.00
	-1.00	**.08**	**-1.53**	**1.15**	**.08**	**.08**	**1.15**
C10	27.00	18.00	26.00	15.00	18.00	18.00	21.00
	1.46	**-.54**	**1.24**	**-1.21**	**-.54**	**-.54**	**.13**
C11	31.00	26.00	24.00	23.00	31.00	22.00	24.00
	1.38	**.04**	**-.50**	**-.77**	**1.38**	**-1.04**	**-.50**
C12	11.00	15.00	14.00	17.00	13.00	12.00	12.00
	-1.17	**.76**	**.28**	**1.73**	**-.21**	**-.69**	**-.69**
Negative affect							
C1	15.00	10.00	27.00	12.00	11.00	14.00	12.00
	.10	**-.76**	**2.17**	**-.42**	**-.59**	**-.07**	**-.42**
C2	16.00	23.00	24.00	20.00	27.00	24.00	21.00
	-1.74	**.24**	**.53**	**-.61**	**1.38**	**.53**	**-.32**
C3	16.00	12.00	12.00	10.00	10.00	10.00	12.00
	2.00	**.13**	**.13**	**-.80**	**-.80**	**-.80**	**.13**
C4	17.00	18.00	12.00	12.00	12.00	11.00	20.00
	.67	**.94**	**-.71**	**-.71**	**-.71**	**-.98**	**1.49**
C5	22.00	17.00	16.00	26.00	10.00	13.00	12.00
	.95	**.08**	**-.10**	**1.65**	**-1.15**	**-.63**	**-.80**
C6	28.00	22.00	18.00	25.00	20.00	44.00	35.00
	.06	**-.59**	**-1.02**	**-.26**	**-.80**	**1.79**	**.82**
C7	19.00	21.00	19.00	15.00	18.00	17.00	21.00
	.20	**1.13**	**.20**	**-1.66**	**-.27**	**-.73**	**1.13**
C8	10.00	11.00	11.00	18.00	15.00	12.00	13.00
	-1.02	**-.66**	**-.66**	**1.84**	**.77**	**-.31**	**.05**
C9	12.00	13.00	15.00	10.00	15.00	13.00	11.00
	-.38	**.15**	**1.21**	**-1.44**	**1.21**	**.15**	**-.91**
C10	31.00	25.00	35.00	19.00	17.00	18.00	29.00
	.87	**.02**	**1.43**	**-.83**	**-1.11**	**-.97**	**.59**
C11	45.00	39.00	27.00	23.00	37.00	19.00	25.00
	1.48	**.86**	**-.39**	**-.80**	**.65**	**-1.22**	**-.59**
C12	16.00	15.00	11.00	15.00	19.00	16.00	11.00
	.45	**.10**	**-1.29**	**.10**	**1.49**	**.45**	**-1.29**

Table I-3. *Individual Raw and Z-scores (in bold) for Positive Well-being Variables, Case by Time*

Positive affect	T1	T2	T3	T4	T5	T6	T7
C1	43.00	44.00	29.00	34.00	36.00	39.00	39.00
	1.01	**1.20**	**-1.67**	**-.71**	**-.33**	**.25**	**.25**
C2	30.00	28.00	27.00	25.00	25.00	26.00	28.00
	1.64	**.55**	**.00**	**-1.10**	**-1.10**	**-.55**	**.55**
C3	29.00	34.00	31.00	24.00	38.00	36.00	36.00
	-.73	**.29**	**-.32**	**-1.75**	**1.11**	**.70**	**.70**
C4	31.00	29.00	26.00	31.00	32.00	27.00	37.00
	.16	**-.39**	**-1.21**	**.16**	**.43**	**-.94**	**1.80**
C5	30.00	33.00	31.00	24.00	36.00	36.00	30.00
	-.34	**.38**	**-.10**	**-1.79**	**1.10**	**1.10**	**-.34**
C6	37.00	31.00	32.00	37.00	32.00	20.00	25.00
	1.04	**.07**	**.23**	**1.04**	**.23**	**-1.71**	**-.90**
C7	25.00	24.00	21.00	15.00	19.00	23.00	22.00
	1.09	**.80**	**-.08**	**-1.85**	**-.67**	**.50**	**.21**
C8	18.00	18.00	15.00	17.00	26.00	31.00	19.00
	-.45	**-.45**	**-.97**	**-.62**	**.95**	**1.82**	**-.27**
C9	20.00	21.00	26.00	19.00	25.00	24.00	26.00
	-1.02	**-.68**	**1.02**	**-1.36**	**.68**	**.34**	**1.02**
C10	21.00	30.00	33.00	36.00	32.00	36.00	30.00
	-1.98	**-.22**	**.36**	**.95**	**.17**	**.95**	**-.22**
C11	48.00	42.00	40.00	46.00	46.00	50.00	49.00
	.58	**-1.05**	**-1.60**	**.04**	**.04**	**1.13**	**.86**
C12	38.00	38.00	36.00	35.00	38.00	38.00	33.00
	.72	**.72**	**-.29**	**-.79**	**.72**	**.72**	**-1.80**
Life satisfaction							
C1	12.00	12.00	10.00	12.00	12.00	12.00	12.00
	.38	**.38**	**-2.27**	**.38**	**.38**	**.38**	**.38**
C2	11.00	7.00	9.00	9.00	6.00	9.00	8.00
	1.59	**-.88**	**.35**	**.35**	**-1.50**	**.35**	**-.26**
C3	10.00	10.00	9.00	8.00	10.00	10.00	10.00
	.54	**.54**	**-.73**	**-2.00**	**.54**	**.54**	**.54**
C4	12.00	9.00	10.00	9.00	11.00	11.00	10.00
	1.54	**-1.16**	**-.26**	**-1.16**	**.64**	**.64**	**-.26**
C5	9.00	12.00	11.00	7.00	13.00	14.00	13.00
	-.92	**.29**	**-.11**	**-1.72**	**.69**	**1.09**	**.69**
C6	11.00	11.00	12.00	10.00	10.00	10.00	8.00
	.57	**.57**	**1.37**	**-.23**	**-.23**	**-.23**	**-1.82**
C7	9.00	9.00	8.00	9.00	8.00	10.00	9.00
	.21	**.21**	**-1.24**	**.21**	**-1.24**	**1.66**	**.21**
C8	10.00	10.00	9.00	6.00	10.00	10.00	10.00
	.48	**.48**	**-.19**	**-2.20**	**.48**	**.48**	**.48**
C9	10.00	9.00	10.00	10.00	10.00	10.00	10.00
	.38	**-2.27**	**.38**	**.38**	**.38**	**.38**	**.38**
C10	10.00	8.00	9.00	10.00	10.00	10.00	10.00
	.54	**-1.20**	**-.73**	**.54**	**.54**	**.54**	**.54**
C11	8.00	8.00	8.00	8.00	8.00	6.00	8.00
	.38	**.38**	**.38**	**.38**	**.38**	**-2.27**	**.38**
C12	12.00	11.00	11.00	10.00	11.00	11.00	11.00
	1.73	**.00**	**.00**	**-1.73**	**.00**	**.00**	**.00**

Table I-4. *Individual Raw and Z-scores (in bold) for MS Symptom Variables, Case by Time*

Symptom frequency	T1	T2	T3	T4	T5	T6	T7
C1	32.00	29.00	35.00	21.00	32.00	36.00	27.00
	.33	**-.25**	**.91**	**-1.80**	**.33**	**1.10**	**-.64**
C2	39.00	39.00	38.00	41.00	33.00	37.00	33.00
	.60	**.60**	**.27**	**1.25**	**-1.35**	**-.05**	**-1.35**
C3	32.00	29.00	29.00	34.00	30.00	21.00	30.00
	.67	**-.07**	**-.07**	**1.16**	**.18**	**-2.04**	**.18**
C4	45.00	49.00	40.00	43.00	37.00	42.00	40.00
	.70	**1.72**	**-.59**	**.18**	**-1.35**	**-.07**	**-.59**
C5	28.00	35.00	23.00	24.00	20.00	24.00	24.00
	.53	**1.98**	**-.50**	**-.30**	**-1.12**	**-.30**	**-.30**
C6	39.00	45.00	35.00	42.00	34.00	37.00	35.00
	.21	**1.67**	**-.77**	**.94**	**-1.01**	**-.28**	**-.77**
C7	44.00	39.00	45.00	48.00	45.00	43.00	44.00
	.00	**-1.85**	**.37**	**1.48**	**.37**	**-.37**	**.00**
C8	36.00	40.00	29.00	21.00	23.00	20.00	32.00
	.94	**1.46**	**.04**	**-1.00**	**-.74**	**-1.13**	**.42**
C9	34.00	31.00	32.00	26.00	28.00	34.00	27.00
	1.12	**.22**	**.52**	**-1.30**	**-.69**	**1.12**	**-1.00**
C10	40.00	41.00	39.00	38.00	36.00	32.00	37.00
	.81	**1.15**	**.48**	**.14**	**-.53**	**-1.86**	**-.19**
C11	48.00	45.00	45.00	43.00	48.00	46.00	44.00
	1.28	**-.30**	**-.30**	**-1.35**	**1.28**	**.23**	**-.83**
C12	47.00	47.00	49.00	45.00	49.00	49.00	49.00
	-.54	**-.54**	**.73**	**-1.82**	**.73**	**.73**	**.73**
Symptom intensity							
C1	29.00	10.00	31.00	8.00	37.00	25.00	15.00
	.61	**-1.08**	**.79**	**-1.26**	**1.33**	**.26**	**-.64**
C2	49.00	39.00	46.00	54.00	40.00	41.00	38.00
	.86	**-.81**	**.36**	**1.69**	**-.64**	**-.48**	**-.98**
C3	34.00	35.00	29.00	34.00	32.00	12.00	34.00
	.49	**.61**	**-.12**	**.49**	**.24**	**-2.20**	**.48**
C4	48.00	76.00	61.00	68.00	49.00	63.00	53.00
	-1.13	**1.57**	**.12**	**.80**	**-1.03**	**.32**	**-.65**
C5	44.00	31.00	28.00	28.00	9.00	15.00	16.00
	1.64	**.55**	**.30**	**.30**	**-1.30**	**-.79**	**-.71**
C6	83.00	74.00	75.00	68.00	64.00	60.00	75.00
	1.51	**.34**	**.48**	**-.42**	**-.94**	**-1.45**	**.48**
C7	62.00	64.00	43.00	60.00	57.00	57.00	61.00
	.61	**.90**	**-2.11**	**.33**	**-.10**	**-.10**	**.47**
C8	24.00	53.00	17.00	19.00	13.00	18.00	31.00
	-.07	**2.05**	**-.59**	**-.44**	**-.88**	**-.51**	**.44**
C9	29.00	23.00	28.00	15.00	21.00	27.00	15.00
	1.09	**.07**	**.92**	**-1.29**	**-.27**	**.75**	**-1.29**
C10	50.00	51.00	39.00	43.00	43.00	35.00	53.00
	.77	**.92**	**-.87**	**-.27**	**-.27**	**-1.47**	**1.22**
C11	76.00	64.00	67.00	64.00	76.00	77.00	72.00
	.89	**-1.19**	**-.67**	**-1.19**	**.89**	**1.06**	**.20**
C12	85.00	85.00	90.00	90.00	83.00	90.00	92.00
	-.83	**-.83**	**.62**	**.62**	**-1.41**	**.62**	**1.21**

Table I-5. *Individual Raw and Z-scores (in bold) for Disability Variables, Case by Time*

FIM	T1	T2	T3	T4	T5	T6	T7
C1		125.00	125.00	125.00	124.00	124.00	125.00
		.65	**.65**	**.65**	**-1.29**	**-1.29**	**.65**
C2		119.00	118.00	118.00	118.00	113.00	113.00
		.91	**.55**	**.55**	**.55**	**-1.28**	**-1.28**
C3		117.00	117.00	117.00	117.00	117.00	117.00
		.00	**.00**	**.00**	**.00**	**.00**	**.00**
C4		107.00	60.00	70.00	70.00	75.00	75.00
		1.92	**-1.01**	**-.38**	**-.38**	**-.07**	**-.07**
C5		122.00	122.00	122.00	122.00	122.00	122.00
		.00	**.00**	**.00**	**.00**	**.00**	**.00**
C6		125.00	125.00	125.00	125.00	123.00	123.00
		.65	**.65**	**.65**	**.65**	**-1.29**	**-1.29**
C7		118.00	119.00	120.00	120.00	120.00	120.00
		-1.79	**-.60**	**.60**	**.60**	**.60**	**.60**
C8		123.00	123.00	121.00	122.00	122.00	122.00
		1.11	**1.11**	**-1.55**	**-.22**	**-.22**	**-.22**
C9		123.00	123.00	124.00	124.00	124.00	124.00
		-1.29	**-1.29**	**.65**	**.65**	**.65**	**.65**
C10		122.00	122.00	122.00	122.00	122.00	123.00
		-.41	**-.41**	**-.41**	**-.41**	**-.41**	**2.04**
C11		116.00	116.00	116.00	115.00	115.00	115.00
		.91	**.91**	**.91**	**-.91**	**-.91**	**-.91**
C12		115.00	115.00	115.00	114.00	114.00	114.00
		.91	**.91**	**.91**	**-.91**	**-.91**	**-.91**
ADL							
C1	28.00	28.00	28.00	28.00	28.00	28.00	28.00
	.00	**.00**	**.00**	**.00**	**.00**	**.00**	**.00**
C2	26.00	22.00	24.00	23.00	24.00	23.00	26.00
	1.30	**-1.31**	**.00**	**-.65**	**.00**	**-.65**	**1.31**
C3	23.00	23.00	23.00	23.00	25.00	27.00	23.00
	-.54	**-.54**	**-.54**	**-.54**	**.73**	**2.00**	**-.54**
C4	18.00	18.00	20.00	17.00	20.00	20.00	20.00
	-.77	**-.77**	**.77**	**-1.55**	**.77**	**.77**	**.77**
C5	23.00	25.00	28.00	28.00	28.00	27.00	28.00
	-1.88	**-.87**	**.65**	**.65**	**.65**	**.14**	**.65**
C6	26.00	24.00	28.00	27.00	27.00	24.00	27.00
	-.09	**-1.36**	**1.18**	**.54**	**.54**	**-1.36**	**.54**
C7	27.00	25.00	26.00	26.00	25.00	26.00	26.00
	1.66	**-1.24**	**.21**	**.21**	**-1.24**	**.21**	**.21**
C8	27.00	28.00	27.00	28.00	27.00	28.00	27.00
	-.80	**1.06**	**-.80**	**1.07**	**-.80**	**1.07**	**-.80**
C9	27.00	28.00	28.00	28.00	27.00	27.00	28.00
	-1.07	**.80**	**.80**	**.80**	**-1.07**	**-1.07**	**.80**
C10	27.00	28.00	28.00	28.00	27.00	27.00	27.00
	-.80	**1.07**	**1.07**	**1.07**	**-.80**	**-.80**	**-.80**
C11	24.00	24.00	22.00	22.00	22.00	24.00	22.00
	1.07	**1.07**	**-.80**	**-.80**	**-.80**	**1.07**	**-.80**
C12	20.00	20.00	20.00	20.00	20.00	20.00	20.00
	.00	**.00**	**.00**	**.00**	**.00**	**.00**	**.00**

Table I-6. *Individual Raw and Z-scores (in bold) for Impairment Variables, Case by Time*

Neurologic dysfunction	T1	T2	T3	T4	T5	T6	T7
C1		5.00	5.00	6.00	7.00	7.00	6.00
		-1.12	**-1.12**	**.00**	**1.12**	**1.12**	**.00**
C2		14.00	14.00	15.00	16.00	16.00	16.00
		-1.19	**-1.19**	**-.17**	**.85**	**.85**	**.85**
C3		9.00	9.00	9.00	9.00	9.00	9.00
		.00	**.00**	**.00**	**.00**	**.00**	**.00**
C4		18.00	21.00	15.00	17.00	17.00	18.00
		.17	**1.70**	**-1.36**	**-.34**	**-.34**	**.17**
C5		6.00	6.00	6.00	6.00	6.00	6.00
		.00	**.00**	**.00**	**.00**	**.00**	**.00**
C6		10.00	10.00	11.00	11.00	11.00	11.00
		-1.29	**-1.29**	**.65**	**.65**	**.65**	**.65**
C7		7.00	8.00	11.00	12.00	12.00	12.00
		-1.48	**-1.04**	**.30**	**.74**	**.74**	**.74**
C8		3.00	3.00	7.00	5.00	5.00	6.00
		-1.14	**-1.14**	**1.35**	**.10**	**.10**	**.73**
C9		7.00	7.00	7.00	7.00	7.00	8.00
		-.41	**-.41**	**-.41**	**-.41**	**-.41**	**2.04**
C10		8.00	5.00	5.00	8.00	8.00	8.00
		.65	**-1.29**	**-1.29**	**.65**	**.65**	**.65**
C11		17.00	17.00	17.00	20.00	20.00	20.00
		-.91	**-.91**	**-.91**	**.91**	**.91**	**.91**
C12		17.00	18.00	19.00	19.00	19.00	20.00
		-1.61	**-.65**	**.32**	**.32**	**.32**	**1.29**
Impairment status							
C1		2.00	2.00	2.00	2.00	2.00	2.00
		.00	**.00**	**.00**	**.00**	**.00**	**.00**
C2		6.00	7.00	7.00	7.00	7.00	7.00
		-2.04	**.41**	**.41**	**.41**	**.41**	**.41**
C3		6.00	6.00	6.00	6.00	6.00	6.00
		.00	**.00**	**.00**	**.00**	**.00**	**.00**
C4		7.00	8.00	8.00	8.00	7.00	7.00
		-.91	**.91**	**.91**	**.91**	**-.91**	**-.91**
C5		2.00	2.00	2.00	2.00	2.00	2.00
		.00	**.00**	**.00**	**.00**	**.00**	**.00**
C6		2.00	2.00	3.00	3.00	4.00	3.00
		-1.11	**-1.11**	**.22**	**.22**	**1.55**	**.22**
C7		6.00	6.00	6.00	6.00	6.00	6.00
		.00	**.00**	**.00**	**.00**	**.00**	**.00**
C8		2.00	2.00	6.00	6.00	6.00	6.00
		-1.29	**-1.29**	**.65**	**.65**	**.65**	**.65**
C9		3.00	3.00	6.00	6.00	6.00	6.00
		-1.29	**-1.29**	**.65**	**.65**	**.65**	**.65**
C10		6.00	6.00	6.00	6.00	6.00	6.00
		.00	**.00**	**.00**	**.00**	**.00**	**.00**
C11		7.00	7.00	7.00	7.00	7.00	7.00
		.00	**.00**	**.00**	**.00**	**.00**	**.00**
C12		7.00	7.00	7.00	7.00	7.00	7.00
		.00	**.00**	**.00**	**.00**	**.00**	**.00**

Table I-7. *Individual Raw and Z-scores (in bold) for Health Change Variables, Case by Time*

Self-rated	T1	T2	T3	T4	T5	T6	T7
C1	3.00	4.00	2.00	4.00	4.00	2.00	4.00
	-.30	**.75**	**-1.35**	**.75**	**.75**	**-1.35**	**.75**
C2	2.00	2.00	2.00	2.00	2.00	2.00	3.00
	-.38	**-.38**	**-.38**	**-.38**	**-.38**	**-.38**	**2.27**
C3	3.00	3.00	3.00	3.00	3.00	3.00	3.00
	.00	**.00**	**.00**	**.00**	**.00**	**.00**	**.00**
C4	4.00	3.00	4.00	4.00	4.00	4.00	3.00
	.59	**-1.46**	**.58**	**.59**	**.59**	**.59**	**-1.46**
C5	3.00	3.00	3.00	4.00	3.00	2.00	4.00
	-.21	**-.21**	**-.21**	**1.24**	**-.21**	**-1.66**	**1.24**
C6	4.00	2.00	4.00	2.00	4.00	2.00	2.00
	1.07	**-.80**	**1.07**	**-.80**	**1.07**	**-.80**	**-.80**
C7	3.00	4.00	2.00	2.00	4.00	4.00	3.00
	-.16	**.95**	**-1.27**	**-1.27**	**.95**	**.95**	**-.16**
C8	3.00	3.00	3.00	3.00	4.00	4.00	3.00
	-.59	**-.59**	**-.59**	**-.59**	**1.46**	**1.46**	**-.59**
C9	3.00	3.00	2.00	4.00	3.00	3.00	3.00
	.00	**.00**	**-1.73**	**1.73**	**.00**	**.00**	**.00**
C10	2.00	3.00	4.00	3.00	2.00	3.00	2.00
	-.94	**.38**	**1.70**	**.38**	**-.94**	**.38**	**-.94**
C11	2.00	2.00	2.00	4.00	3.00	3.00	2.00
	-.73	**-.73**	**-.73**	**1.82**	**.54**	**.54**	**-.73**
C12	3.00	3.00	3.00	1.00	4.00	3.00	2.00
	.30	**.30**	**.30**	**-1.80**	**1.35**	**.30**	**-.75**
Other-rated							
C1			3.00	4.00	4.00	3.00	4.00
			-1.10	**.73**	**.73**	**-1.10**	**.73**
C2			2.00	3.00	2.00	2.00	4.00
			-.67	**.45**	**-.67**	**-.67**	**1.57**
C3			3.00	3.00	3.00	3.00	3.00
			.00	**.00**	**.00**	**.00**	**.00**
C4			3.00	4.00	4.00	4.00	3.00
			-1.10	**.73**	**.73**	**.73**	**-1.10**
C5			3.00	3.00	4.00	3.00	4.00
			-.73	**-.73**	**1.10**	**-.73**	**1.09**
C6			3.00	2.00	3.00	2.00	3.00
			.73	**-1.10**	**.73**	**-1.10**	**.73**
C7			3.00	2.00	4.00	4.00	3.00
			-.24	**-1.43**	**.96**	**.96**	**-.24**
C8			3.00	2.00	4.00	3.00	3.00
			.00	**-1.41**	**1.41**	**.00**	**.00**
C9			3.00	3.00	3.00	3.00	3.00
			.00	**.00**	**.00**	**.00**	**.00**
C10			3.00	3.00	2.00	3.00	3.00
			.45	**.45**	**-1.79**	**.45**	**.45**
C11			3.00	4.00	3.00	3.00	3.00
			-.45	**1.79**	**-.45**	**-.45**	**-.45**
C12			3.00	2.00	4.00	3.00	3.00
			.00	**-1.41**	**1.41**	**.00**	**.00**

APPENDIX J: NOTES

1. The present study does not specifically aim to identify avenues for therapeutic intervention in MS patients. Coping and appraisal, which are viewed as important in terms of adjustment to MS, were not included in the present model which has a more general focus. Several reasons contributed to the decision not to include this construct. Firstly, at the inception of this project in 1989, many promising models on the relationship between psychological factors and health outcomes did not expressly include coping as a construct (eg. Antonovsky, 1979; Ben-Sira, 1984; Kobasa, 1979). As in the present model, their focus was on dispositional and/or social support moderators of the stress-health relationship, and coping was inferred from the health outcome. Secondly, the present model, in the main, was concerned with tracking factors that change over time. In 1989, researchers were strongly influenced by Lazarus and Folkman's model of coping (Lazarus & Folkman, 1984) which emphasised cognitive coping styles, rather than process, and viewed these styles as relatively stable. Thirdly, research on the relationship of coping styles to psychological well-being in MS patients demonstrated only weak associations. For example, Hickey and Greene (1989) failed to find significant correlations between problem-focused and emotion-focused coping with depression and hopelessness. Lastly, a sample of chronic illness patients was likely to be small and hence efforts were made to limit the number of constructs in this study. The inclusion and exclusion of constructs was decided on a priority basis in terms of their conceptual appropriateness for a correlational change model. The present model is intended to represent relationships among psychosocial and physical health in MS and is not intended to represent other chronic illnesses, although at the construct level there may be some relevance for other illness groups. There has been no attempt to generalise this model to other chronic illness groups and hence a comparison group or control group was deemed unnecessary.

2. The decision to use multiple regression analysis despite the small sample size and the large number of independent variables was guided by a conservative approach to data analysis. A strategy was needed to deal with conflicting pressures. On the one hand, it was necessary to minimise the number of analyses to avoid inflating alpha, control for correlations among

predictor variables, test for interactions, and avoid over fragmentation of the model. On the other hand, using moderated regressions with a small sample size and relatively large subsets of variables is likely to produce Type II errors, where significant findings may be missed. The approach adopted was conservative in that it favours Type II errors, whereas a more fragmented approach to analysis, although limiting the number of independent variables in an equation, would produce Type I errors, leading to the over interpretation of findings of questionable significance.

3. The within-subject approach to analysis as described by Bolger et al. (1989) is used to focus an analysis "...on within-person variation and to purge the data of the effects of individual difference variables that create between-person variation" p. 810. Deviation scores are created by subtracting the within-person mean from each serial score. Analyses are then based on pooled within-person variation. Although Bolger et al. contend that this method eliminates between-subject variability, this assumption appears to be only partially correct. Levels of individual variability are removed from the data, but between-subject variability resulting from individual differences in change scores remain. In the present study, the unit of analysis used in these analyses was the episode rather than the subject, resulting in the sample being episodes of change rather than people. Seven data collection times x 12 subjects effectively provided 84 episodes. The time structure of the data was maintained, but not in terms of specific time points. Although, the sample of 84 is larger than the sample of 45 used in the cross-sectional analyses, some of the same problems inherent in using a small sample with a relatively large number of independent variables recur here. The arguments used in Note 2, for a conservative approach to analysis, apply again. Unlike Bolger, the present analysis included some variables that were not change scores. It may seem that these more stable scores cannot be correlated with the change scores because they contain no within-subject variability. However, they do contain variability across subjects and therefore can be correlated with the change scores. The restricted variability of the stable scores will, nevertheless, result in a conservative estimate of the relationship between change variables and stable variables.